Grasp Your Pain: A Tangible Tool to Explore the Logging and Assessment of Pain

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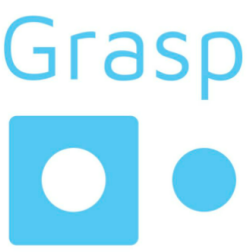
Scientific environment

This study was carried out at the Department of Information Science and Media Studies at the University of Bergen. The work was made in collaboration with Grasp AS and Sykehuset Østfold (Østfold Hospital).



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Abstract

Pain is a subjective and innate experience that can be difficult to describe. Chronic pain is associated with decreased quality of life, and it is prevalent in cancer populations. With a growing elderly population, the global cancer burden is expected to rapidly advance in the coming years. Expressing pain and symptom experiences is essential for patients to receive proper treatment and care. Self-reporting tools are useful and reliable measures of patients' symptoms. A commonly used assessment form in palliative care is ESAS-r, the revised Edmonton Symptom Assessment System. It lets the patient rate a list of symptoms, on a scale from 0 to 10, depending on their intensity. Research suggests that ESAS-r only captures a snapshot of the patients' symptom profile, and that is burdensome to patients and clinical staff. There is a need for self-assessment tools that are easy to use, non-intrusive, and can be used in situ. The research in this thesis explores the use of a tangible tool (Grasp), and squeezing as an input method to log pain/symptoms experiences. Grasp consists of a small stone-like object. When squeezed, it logs the time and duration of the interaction. Squeezes are then visualized on an accompanying interface. Through a Mixed Methods Research approach, a pilot study and clinical trial were conducted. The former gathered participant (N=8) opinions on Grasp, and the use of squeeze duration to log experiences. The latter explored the implementation of Grasp alongside ESAS-r in a cancer ward (*nurses* = 6, *patients* = 8). Two broad research questions were examined: RQ1: *How can tangible interaction through Grasp support the logging of experiences?* and RQ2: *How do palliative cancer patients and nurses experience Grasp as a tool for the logging, assessment, and communication of pain and symptoms compared to ESAS-r?* Findings from the pilot suggest that there is potential in using Grasp and squeeze duration to log events, and that interacting with the tool potentially can help distract or externalize from negative experiences. Participants from both studies found Grasp easy to use, and visualizations intuitive and meaningful. Nurses and patients were generally satisfied with Grasp as a tool, and it helped paint a wider image of the patients' symptoms compared to ESAS-r alone. However, patients were sometimes too ill to use Grasp, and the research was limited by barriers related to clinical environments. Further research is needed to explore the potential of tangible interaction and squeezing as an input method with other patient groups. There is also the aspect of the affective interaction that should be investigated further.

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Abbreviations

EMA Ecological Momentary Assessments

ePRO Electronic Patient-Reported Outcome

ESAS Edmonton Symptom Assessment System

ESAS-r Edmonton Symptom Assessment System Revised

FPS-r The Faces Pain Scale-Revised

GUI Graphical User Interface

HCI Human-Computer Interaction

HCP Health Care Provider

ICT Information and Communication Technology

IoT Internet of Things

mHealth Mobile Health

MMR Mixed Methods Research

MWU Mann-Whitney U Test

NRS Numeric Rating Scale

PDA Personal Digital Assistant

PRO Patient-Reported Outcomes

QoL Quality of Life

TUI Tangible User Interface

VAS Visual Analog Scale

VRS/VDS The Verbal Rating/Descriptor Scale

Chapter 1

Introduction

The majority of people have or will experience pain at some point in their lives. Although it can cause suffering and frustration, it is an essential experience in human existence (*Käll*, 2013). It serves as a warning system to protect and alert us of potential dangers, and it often disappears or diminishes when the threat or source of pain is removed. The International Association for the Study of Pain defines pain as:

> An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage (*IASP*, 2020).

For the first time since 1979, IASP has revised its definition of pain in hope of improving the assessment and management of those with pain, and to better communicate the nuances and complexity of pain (*IASP*, 2020). Pain is is universal but experienced by individuals in a subjective and personal manner. *Gilam et al.* (2020) describe pain as a "reflective process that in many cases (but not always) is a result of perceiving nociceptive information". It is a concept individuals learn over time, and people might experience the same painful stimulus differently depending on biological, psychological, and socio-cultural factors (*Mills et al.*, 2019). Additionally, pain is influenced by cognitions including thoughts, beliefs, and expectations about it (*Gilam et al.*, 2020). It is often accompanied by other symptoms, and its individuality makes reporting and managing a perplexing task. *Biro* (2013) argues that the seemingly inexpressible experience of pain is a product of the lack of intentionality, it is not routinely connected to a physical object, and its innate nature, it is conceptually elusive and private.

Pain is commonly dichotomized into chronic and acute pain, where the latter acts as an alarm mechanism to protect our bodies from harm. Acute pain is often a direct result of illness or bodily damage; Imagine putting your hand on a hot stovetop (*FHI*, 2019). It can also be a consequence of trauma, surgical interventions, and some diseases. Usually, the pain will cease with proper medical treatment, and the report of pain typically stops before the healing is complete (*Loeser and Melzack*, 1999). Occasionally, pain becomes chronic. Chronic pain is defined as pain that persists or recurs for more than three months (*WHO*, 2021). It encompasses arthritis, migraine, lower back or neck pain, cancer, and conditions resulting from injury, failed surgery, or other physical trauma to name a few (*Adams et al.*, 2017). Chronic pain is complex as the individual undergoes neurobiological, psychosocial, and social changes that can help perpetuate the pain (*Lumley et al.*, 2011). In spite of the evolutionary value of pain, unrelieved pain has destructive consequences; Chronic pain is associated with decreased

Quality of Life (QoL) by interrupting work and social relationships, opioid dependence, and poor mental health (*Goldberg and McGee*, 2011; *Zelaya et al.*, 2020). About 30% of the adult Norwegian population suffers from chronic pain, and it is responsible for 50% of all disability benefits cases (*FHI*, 2019). Despite few estimates on chronic pain worldwide, about 1 in 10 adults are diagnosed with it every year, and the prevalence in Europe and the US has been measured at 20% and 20.4% respectively (*Goldberg and McGee*, 2011; *Zelaya et al.*, 2020). From a societal perspective, it poses a tremendous economic burden (*Gaskin and Richard*, 2012).

Estimates suggest that two-thirds of advanced, metastatic, and terminal cancer patients suffer from pain, where half of them experience moderate to severe pain (*van den Beuken-van Everdingen et al.*, 2016). Every year about 19.3 million new cancer cases occur worldwide, and it is a leading cause of death with 10.0 million cancer deaths in 2020 (*Sung et al.*, 2021). The global cancer burden is expected to increase rapidly in coming years, due to demographic changes and a growing elderly population. Patients with cancer experience a range of symptoms that affect their QoL, and impair physical and psychological functioning (*Portenoy and Lesage*, 1999). Symptoms range from pain, anxiety, nausea, lack of appetite, and fatigue to name a few (*Nayak et al.*, 2015). Pain can cause or exacerbate other symptoms, and cancer patients have reported that it affects the performance of everyday activities, prevents concentration and thinking, and is distressing (*Burton et al.*, 2014; *van den Beuken-van Everdingen et al.*, 2016).

Due to the subjective nature of pain and the severe consequences it has on those suffering from it, there is a pressing need to research and develop tools that enhance pain diagnosis, care, and treatment. IASPs revised definition acknowledges that verbally describing pain is only one of several behaviors to express and recount pain (*IASP*, 2020). How then, can individuals best convey their pain to the environment? Self-reporting, or Patient-Reported Outcomes (PROs), are considered essential in assessing and treating pain, and they provide accurate and reliable evidence of the existence of pain and its intensity (*Adams et al.*, 2017; *Karcioglu et al.*, 2018). Everyday self-monitoring of chronic conditions, including the logging and interpretation of symptoms, enables patients to take an active part in their own care (*Price et al.*, 2018). It may also reduce patient hospitalization and readmissions (*McBain et al.*, 2015). Several tools exist for patients to report and assess their pain. In particular, numeric, visual or verbal rating scales, bodymaps, and diaries, or combinations of these (*Hawker et al.*, 2011; *Morren et al.*, 2009). With the expanding field of Mobile Health (mHealth), an abundance of new tools to measure and log your health have emerged (*Vardeh et al.*, 2013). There has been an increase in health-related applications, where the pervasiveness of smartphones permits repeated, in situ sampling, of patients' pain/symptom experiences. This type of continued, real-time sampling of individuals' experiences in their natural environments is called Ecological Momentary Assessment (EMA). It helps minimize recall bias and maximizes ecological validity of self-reports (*Shiffman et al.*, 2008). It can also reduce bias on the collector side, by lessening the workload and interaction required with researchers or Health Care Providers (HCPs) during data collection (*Hernandez et al.*, 2016). In spite of this, several available mHealth procedures have yet to be subject to proper assessment and validation (*de la Vega and Miró*, 2014).

Pain is often assessed in terms of its intensity through numbers or descriptors (*Karcioglu et al.*, 2018). This approach to may be insufficient in properly reflecting patients experiences. It is challenging to describe pain with measures that may show ambi-

guity in use, due to different individual interpretations (*Fyhn and Buur*, 2020). *Fyhn and Buur* (2020) have investigated alternative ways for chronic patients to express their pain. They argue that there is a need for a shared language for individuals to express their pain experiences to their environment. Through the use of *material metaphors*, like dolls and clay, different types of pain experiences were identified, such as "burning pain" and "stabbing pain". Material metaphors allow for a negotiation of the meaning of such expressions and can contribute nuances to the verbal or numeric descriptions of pain.

Even though pain intensity is the most salient aspect of pain, it is not the only one. Cancer pain, for example, is complex and assessment of its many domains requires a multidimensional approach to promote proper cancer pain management (*Burton et al.*, 2014). When cancer patients are hospitalized and during their stay, they are often screened using ESAS-r, the revised version of the Edmonton Symptom Assessment System (ESAS). This is the recommended survey form used with palliative patients in Norway (*Helse Bergen*, 2021). ESAS-r asks the patient to rate a list of common symptoms, one of which is pain, on a numeric scale from 0 (*no symptom*) to 10 (*worst possible symptom*). Regardless of the adoption and acknowledgment of the tool, it only reports the intensity of the symptoms, and it can be labor-intensive to frequently distribute, collect and review. Research suggests that even daily administration of ESAS-r only captures a snapshot of the patients' symptom profile, and that is burdensome to patients and staff (*Lucey*, 2012).

There is a need to explore alternative ways for patients to log, assess and communicate their pain and symptoms in a safe, easy and non-intrusive manner. Likewise, in order to provide proper treatment and care, HCPs need to be aware of and understand patient's conditions and their fluctuations. Self-reporting tools are available, yet, several of them have limitations. In particular, several are unidimensional, can only be applied to certain populations, or are burdensome and labor-intensive to use and administer (*Hawker et al.*, 2011). Busy clinical environments also impose limitations and requirements for the adaptation of new tools (*Price et al.*, 2018). Apart from providing accurate assessment and being low burden, there is a need for tools that can be deployed in situ, encourage recurrent use, are inconspicuous and can be customized to users needs (*Adams et al.*, 2017). State-of-the-art approaches have tried to address the issues of existing tools through innovative ideas and new methods. For instance, work has been done on tangible tools for pain logging and reporting. Regardless, much of it is restricted to high-functioning prototypes, and have not been incorporated in a clinical context over an extended period of time (*Adams et al.*, 2018; *Schaffner et al.*, 2012).

1.1 Problem statement and objectives

This research is split into a pilot study and a clinical trial, examining different aspects of the same goal. The overall aim has been to explore the use of a tangible tool and squeezing as an input method, to log symptom experiences. Focus has especially been on palliative cancer patients, and the logging and assessment of their symptoms (specifically pain). *Grasp* is a small ball-like silicon object with an accompanying visualization software (*Grasp*, 2021a). When Grasp is squeezed the time and duration of the interaction are recorded and stored. Data can be transferred via Bluetooth to a mo-

bile application, and from there to the web interface. In both places, interactions are visualized allowing the user to see overviews and details of past events.

The pilot study explores users initial thoughts and impressions of Grasp, and how tangible interaction and squeezing as an input method can be used to log experiences. The non-randomized clinical trial investigates if and how Grasp, in addition to ESAS-r, can support palliative cancer patients and nurses in logging, assessing, and communicating symptoms. Additionally, the research aims to identify nurses and patients barriers and needs in clinical symptom assessment. Tangible tools using novel input methods for pain and symptoms logging is a developing but underexplored field, which can gain from additional contributions.

1.2 Research questions

Two broad research questions with accompanying sub-questions were formulated to guide the work.

RQ1: How can tangible interaction through Grasp support the logging of experiences?

- 1A: Can participants consistently produce squeezes of a given duration?
- 1B: How can visualizations of squeeze data support the assessment and reflection of experiences?
- 1C: What are participants' initial impressions of the Grasp hardware and software?

RQ2: How do palliative cancer patients and nurses experience Grasp as a tool for the logging, assessment, and communication of pain and symptoms, compared to ESAS-r?

- 2A: What is the current practice of symptom assessment at the cancer ward?
- 2B: What are the needs and barriers, nurses and patients face in symptom assessment?
- 2C: What are the challenges and opportunities of Grasp as experienced by patients and nurses?

1.3 Contribution

The specific contributions of this research are:

1. An extensive literature review of existing tools and approaches to pain and symptom reporting. This includes literature on traditional and unconventional approaches, their pros and cons, and related topics such as affective interaction, tangibles, and fidget tools.
2. Results from a pilot study exploring participants' initial thoughts on Grasp and the use of squeeze duration to log experiences. The use of squeeze duration differs from similar research like the work by *Adams et al.* (2018), where they applied squeeze pressure.

3. Elaborate data and insights from the clinical trial at a Norwegian cancer ward, where Grasp was used by patients and nurses in the daily logging and assessment of cancer symptoms. To the best of my knowledge, tangible symptom logging tools that use squeezing as an input method, have yet to be tested in a clinical environment over a period of time.

1.4 Thesis outline

This thesis is structured accordingly:

Chapter 2: Background presents an overview of relevant literature and research on traditional pain scales, mHealth, pain and symptom management in cancer patients, and affective and tangible interaction.

Chapter 3: Grasp includes a short introduction to Grasp and a summary of the existing research that took place during its development.

Chapter 4: Methodology and Methods presents an introduction to Mixed Methods Research, an outline of the studies, and descriptions of the research methods used.

Chapter 5: Pilot Study Data and Results reports the quantitative and qualitative results from the pilot study.

Chapter 6: Clinical Trial Data and Results is dedicated to the findings gathered from questionnaires and interviews with patients and nurses partaking in the trial.

Chapter 7: Conclusion and Further Work summarizes the work and discusses where the road leads next.

Chapter 2

Background

Self-reporting is essential in assessing and treating pain given its subjective nature (*Adams et al.*, 2017). Subjective pain data can assist clinicians in treating and caring for patients, by monitoring the effects of prescribed analgesia, and patients in gaining a better understanding of their overall condition (*Price et al.*, 2018). For some patients, completing pain scores even helps cope with their pain (*de Wit et al.*, 1999). Still, patients may face difficulties in converting pain into objective measures, and there is no guarantee that family, friends, and health personnel can relate to the outputs of such scales (*Adams et al.*, 2017; *Fyhn and Buur*, 2019). This chapter presents an overview of relevant research and literature. It includes a summary of some widely used pain scales and diary methods, an overview of pain and symptom management in cancer and palliative care, an introduction to mHealth and Telehealth, as well as research on tangible tools, affective interaction, and state-of-the-art approaches.

2.1 Barriers to pain and symptom management

The ability to share and express pain and symptoms is crucial in bringing patients out of their solitude. Still, several barriers interfere with the reporting and assessment both related to the patient, providers, and healthcare systems (*Wilkie and Ezenwa*, 2012). Although we can imagine pain, recollect it, and even resonate with another person's experience and expressions of pain, the subjectiveness makes it hard to verbally articulate in a precise manner (*Gilam et al.*, 2020). Children, older adults, and those with cognitive impairment are particularly vulnerable as they may not be able to articulate their pain experiences at all. For chronic pain patients, it is especially challenging to communicate pain to the environment, what the pain feels like, or whether it has become better or worse (*Fyhn and Buur*, 2019). There is also the problem of recall bias when asked typical questions at the doctors office: "how intense was the pain, on average, this week?". *de Wit et al.* (1999) found that patients tend to overestimate their average pain intensity if asked in retrospect. This is also seen with other symptoms reported in hindsight (*Haque et al.*, 2015). Patients' answers are often affected by systematic bias enabled by memory heuristics (*Shiffman et al.*, 2008). To illustrate, the *availability heuristic* states that events easily recalled are believed to happen more frequently. The current mental state of individuals has also been shown to impact memory retrieval, and studies suggest that people are more likely to retrieve negatively valenced

information when they are in a negative mood (*Shiffman et al.*, 2008).

When admitted to the hospital or in dialogue with healthcare workers, patients can be reluctant to express their pain and symptoms, or ask for analgesic (*Francke and Theeuwen*, 1994). This inhibition may be attributed to patients conception of pain, symptoms, treatment and analgesics (e.g. fear of addiction and side effects), insecurity and lack of assertiveness, and negative attitudes of HCPs (*Francke and Theeuwen*, 1994; *Nayak et al.*, 2015). Another barrier to pain management is the idea that "good" patients do not complain (*Nayak et al.*, 2015). Even though nurses are trained and skilled in their profession, they might fail to recognize patients pain, and thus misjudge their pain intensity when relying on their own observations (*de Rond et al.*, 2000). Systematically prompting patients to report their pain can increase agreement between patients and nurses' pain ratings, and help nurses take appropriate measures to alleviate the pain (*de Rond et al.*, 2000; *Francke and Theeuwen*, 1994). Frequently querying patients is nonetheless labor-intensive in already busy clinical environments and nurses' medical records have been found to be incomplete (*Price et al.*, 2018).

2.2 Pain scales and diaries

With the pressing need to address the subjective notion of pain, plentiful scales and tools have emerged. A majority of them are unidimensional focusing on pain intensity. Others offer more elaborate assessments by including pain location, interference with daily functioning, and related symptoms (*Scher et al.*, 2020).

2.2.1 Traditional pain scales

Hawker et al. (2011) and *Karcioglu et al.* (2018) have identified and summarized some of the most popular scales and tools for pain assessment. These are presented in the following section.

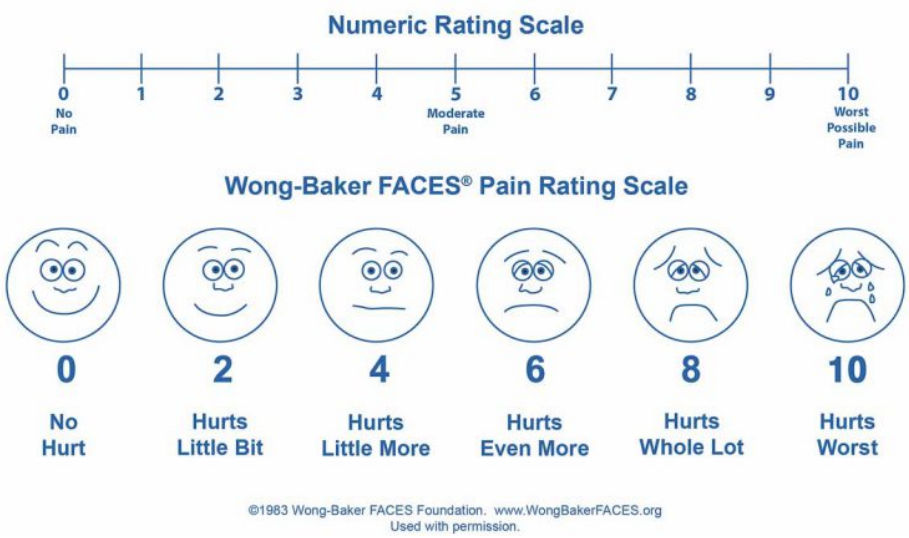
Unidimensional scales

The Visual Analog Scale (VAS) and similar scales, have long been prominent in the field of pain assessment. It is one of the most widely used tools for estimating the severity of pain and the extent of pain relief, either currently or over the past 24h. VAS uses a 10 cm horizontal or vertical line to represent a range between two verbally described outer points, *no pain* and *worst possible pain*. The patient marks a point on the line, and the administrator measures the length from *no pain* to the indicated spot in millimeters. This produces a score between 0-100. The tool is intuitive to use and faces minimal translation issues. Yet, it is only suitable when patients are able to physically mark or visualize the line. The measuring of a score can also introduce human errors, and ambiguous results occur if the mark is not clearly present within the anchors of the scale (*Byrom et al.*, 2022).

Another validated and popular tool is the Numeric Rating Scale (NRS) where pain intensity is rated on a scale from 0 (*no pain*) to 10 (NRS-11) or 100 (*worst possible pain*, NRS-101). It is the most frequently used tool for patients with cancer-related pain, and the data produced are easily documented. It is represented as a horizontal

bar as depicted in Figure 2.1. The NRS is usually used to measure the average pain intensity or the pain intensity of the past 24 hours. Both the VAS and the NRS are unidimensional scales. Given that the patient can relate to numbers or mark a line, these scales have a low respondent burden and are quick to complete. Studies suggest that the NRS is the preferred tool among chronic pain patients, but that patients have diverse views on the range of the scale and the inferred meaning of intermediate and endpoints (*de Williams et al.*, 2000). A study on chronic pain patients using six different pain scales found that while the scales are "more similar than they are different", the NRS-101 outperformed the VAS (*Jensen et al.*, 1986). It is easy to score, can be administered both verbally and on paper, and has 101 response categories. In comparison, VAS cannot be presented verbally, it requires a two-step scoring, and it was the only scale where incorrect responding was related to age. Elderly or populations with disadvantages can face considerable difficulties when applying the VAS. Studies suggest it can be prone to visual cofounders for high pain levels (*Schaffner et al.*, 2012).

Figure 2.1: NRS and Wong-Baker Faces (Wong-Baker FACES Foundation, n.d.)



Some scales stray away from the numerical approach to pain. The Verbal Rating/Descriptor Scale (VRS/VDS) scale estimates pain intensity by letting patients pick a word from a list of descriptors (e.g. *mild*). This may benefit patients who experience severe pain, but does not express their discomfort, though it arguably provides less precision than numeric scales. A more comprehensive scale is the the Wong-Baker Faces Pain Rating Scale. This scale uses depictions of facial expressions to indicate varying levels of pain. It was originally developed for children as they struggled to use numbers, but can be applied to adults and even the elderly who sometimes suffer cognitive impairment (*Rodríguez et al.*, 2016; *Wong-Baker FACES Foundation*, n.d.). It consists of six faces accompanied by a number from 0-10, and verbal descriptors to guide the user and administrator. Younger children can mistakenly assume that there is a "right" and "wrong" answer like picking the happiest face (*Morton*, 1997).

Multidimensional scales

Whereas the aforementioned scales are considered cheap and generally easy to use, they can suffer from recall bias when administered in retrospect, they are unidimen-

sional, and some cannot be administered verbally, making them less accessible. This approach is inadequate in comprehensive pain assessment which should encompass the multidimensional evaluation of pain perception (*Karcioglu et al.*, 2018). The McGill Pain Questionnaire is a multidimensional scale of perceived pain in adults with chronic pain. It evaluates both the quality and quantity of pain through unique pain descriptors. Disadvantages include being time-consuming, and the administrator and patient must have a rich vocabulary. The descriptors selected can also be affected by gender and ethnic differences. Pain body maps, manikins, or diagrams are other forms of multidimensional pain tools. Here the patient can rate the intensity of the pain and also point out its spatial location on the body (*Jaatun et al.*, 2013).

There is much to consider when applying different pain scales, including who the target users are and how detailed information is needed about the pain. One must also be mindful of interchanging and combining different scales as they do not necessarily agree with each other, despite their individual validation (*Bailey et al.*, 2007). If a patient is unable to self-report their pain reliably, under sedation or in extreme pain, data concerning patients heart rate, respiratory rate, and blood pressure may be used as cues for assessment. One can also consider behavioral parameters like body position, crying, and facial expressions, as seen in scales for children, let alone how pain affects daily activities like sleeping and eating (*Argüello Prada*, 2020; *Morton*, 1997).

2.2.2 Diaries

Diaries have long traditions within fields like psychology, and they are used to investigate ongoing social, psychological, and physiological processes within everyday life (*Bolger et al.*, 2003). Pain diaries may supply more detailed, long-term, and in situ assessments of pain, compared to their pain-scale counterparts that often rely on HCPs to be administered. They are usually completed several times a day, either during predefined points in time, when the user wants, or after certain events (*Morren et al.*, 2009).

While diaries allow for continuous pain assessments, they can suffer from recall bias and be prone to misreporting and low adherence if poorly designed (*Adams et al.*, 2017). Diaries also call for detailed instructions to ensure that users fully understand how to utilize them, and they demand commitment and dedication (*Bolger et al.*, 2003). To counter this, they are often designed to be short and time-efficient, even if it compromises in-depth reporting. There is also no agreed-upon set of questions to be used in pain diaries. Consequently there is little knowledge as to whether any of the existing measures are valid and reliable (*Morren et al.*, 2009).

de Wit et al. (1999) found that patients' compliance with pain diaries was high (86%) even in seriously ill patients, regardless of age, level of education, pain duration, and pain pattern. They studied (N = 159) cancer patient's use of an at-home pain diary over two months. Present pain intensity was recorded using a NRS-11, once every morning and evening. All participants were familiar with self-reporting of pain as they were previously admitted to a cancer hospital. Almost 60% of patients reported that completing pain scores helped them to cope with their pain. It was also found that patients tend to systematically overestimate their average pain intensity when asked about it retrospectively.

2.2.3 Electronic pain scales and diaries

Several electronic versions of both analog pain scales and diaries have been developed. Sharing and processing large quantities of paper data depends on human resources, and can be time-consuming and cumbersome (*Jaatun et al.*, 2013). Electronic devices offer benefits with regards to data collection, quality, storage, and management, and the tracking of symptoms over time, and they may facilitate follow-up of patients outside the hospital (*Hjermstad et al.*, 2012).

Electronic scales

Digital scales have some apparent benefits. In particular automatic data transfer and analysis facilitating real-time in situ data collection. Still they often require special equipment and can be expensive to implement (*Wood et al.*, 2011). One must also be careful when transitioning between paper and electronic scales, as there is no guarantee that the mediums are interchangeable without thorough assessment.

A study comparing electronic and paper versions of The Faces Pain Scale-Revised (FPS-r), among 202 hospitalized children found no significant differences in pain scores between the versions (*Wood et al.*, 2011). The FPS-r is similar to the Wong-Baker Faces Scale. The electronic version was preferred by 87.4% of those who stated their preference. Promising results for other scales have also been found. For example *Sánchez-Rodríguez et al.* (2017) report that through their study of 180 school children, that the electronic and paper versions of the NRS-11 and VAS can be used interchangeably. Other research on the use of an electronic VAS application (eVAS) found that the eVAS appears to be interchangeable with the original paper version (*Turnbull et al.*, 2020). 109 healthy participants used both versions to rate their pain when pressure was applied to their thumb. Excellent inter- and intra-method reliability between the two measures was found with adults, and moderate-to-good reliability for adolescents and children. Several studies support the interchangeability and equivalence of electronic and paper VASs (*Byrom et al.*, 2022).

Electronic diaries

Electronic diaries have gained popularity as data can be collected and reviewed instantly enabling EMA. *Morren et al.* (2009) have reviewed 62 e-diary publications, published between 1991-2006, for momentary assessment of pain. They found that compliance was generally high, despite the publications varying greatly when it comes to the population of interest, the type of e-diary applied, diary length, and the number of daily diaries administered for how long. The mean compliance rate was 83%, and it was positively associated with shorter diaries, age, financial compensation, having an alarm reminding users to log pain, and providing a users manual. A randomized trial of electronic versus paper pain diaries in children with chronic pain, found that the electronic diaries showed significantly greater compliance and accuracy (*Palermo et al.*, 2004). Studies also suggest a preference for e-diaries. *Marceau et al.* (2007) studied 36 chronic pain patients monitoring their pain, mood, activity interference, and medication using a paper or an e-diary. Patients used both diary versions separately, for two weeks each. Data recording was significantly easier on the e-diary, which was also the

one patients preferred. They reported that the e-diary enabled them and their doctors to make adjustments in their treatment following changes in pain status.

Electronic diaries mitigate some of the shortcomings of paper diaries concerning compliance, satisfaction, and "hoarding" where users complete missed diary entries in retrospect and all at once. They also have the advantages of automatic date- and time-stamping, randomization of item presentation, instant data access, and audio and visual reminders (*Morren et al.*, 2009). Diaries that can be downloaded to smartphones are practical as they can be brought along everywhere. Nonetheless, e-diaries are not free of drawbacks. The ones that require extra hardware can impose an additional burden on the user, and may be susceptible to technical malfunctions. E-diaries may also be hard to use during a pain episode or for patients with visual disabilities (*Adams et al.*, 2017; *Palermo et al.*, 2004; *Vardeh et al.*, 2013). Constant reminders to log pain several times a day could also cause patients to rush or skip through the diaries, affecting the data.

2.3 Cancer pain and symptom management in palliative care

Cancer pain varies throughout the cancer trajectory. It is caused by direct tumor involvement, diagnostics or therapeutic procedures, side effects, toxicities of treatment, or a combination of these (*McGuire*, 2004). While literature estimates on the occurrence of cancer pain varies, studies generally seem to find occurrence rates to be higher, 80-100 %, in palliative care (*McGuire*, 2004). Most patients with chronic pain develop additional symptoms (*Portenoy and Lesage*, 1999). Advanced cancer patients frequently suffer from fatigue, anorexia, constipation, dyspneas, nausea, and vomiting (*Shoemaker et al.*, 2011). Non-pain symptoms are frequent in cancer patients across all phases of the disease. The prevalence of moderate-to-severe symptoms increases along with a decrease in QoL, following the course of the disease and treatment (*van den Beuken-van Everdingen et al.*, 2009). Inadequate assessment and unrelieved symptoms affect both patients and their closest relatives. *Jonasson et al.* (2009) found that widowers of female cancer patients had a higher risk of sleep-related problems, four to five years after the loss of their wife, if the wife had suffered unrelieved anxiety or pain at the end of her life.

Palliative care

Effective treatment of pain is a cornerstone in palliative care, that is a therapeutic approach, focusing on caring for patients with incurable illness and their families (*Portenoy and Lesage*, 1999). It aims to improve their QoL throughout the disease trajectory and helps them face the prospect of death. It is often used interchangeably with *supportive care* described as "the prevention and management of the adverse effects of cancer and its treatment", which includes management of physical and psychological symptoms and side effects, across all stages of the cancer trajectory (*Aapro et al.*, 2020).

Tools exist for pain/symptom management in palliative care. Nonetheless, studies suggest that symptoms are inadequately assessed and managed, and that there is

a need for broader conceptualizations and measurement (*Wilkie and Ezenwa*, 2012). *Strömgren et al.* (2001) compared the symptoms reported by palliative cancer patients' through self-reports, with their corresponding medical records, as reported by their doctors. It included, among other forms, ESAS. The aim was to estimate the extent to which symptoms experienced by patients were recognized by their doctors. The study revealed considerable discrepancies between the records. Patients reported symptoms and problems more often than their doctors, and there was low concordance with medical records. An exception was pain that had good concordance across the reports.

Shoemaker et al. (2011) have proposed a set of principles to guide HCPs in the symptom management of advanced cancer patients. Principles include to prioritize symptoms according to their severity, reassess the patient frequently, and be mindful of the patients age, fragility, timing, costs, and dosage when deciding upon, distributing, or discontinuing drugs as well as non-pharmacological interventions. HCPs should show interest in patients' symptoms and ask them directly about them in a positive and detailed fashion, in a language understandable to them. As cancer patients face barriers in expressing their symptoms, they must consequently and repeatedly be encouraged to do so. Effective communication between patients and HCPs is fundamental, and it can enhance the patients' confidence in managing symptoms (*Donovan et al.*, 2005). In a study of women experiencing symptoms associated with ovarian cancer, it was revealed that only half of them (N = 279) had ever received symptom management recommendations from HCPs for their most burdensome symptoms (*Donovan et al.*, 2005).

ESAS and ESAS-r

The Edmonton Symptom Assessment System is not a pain scale per se, but assesses a list of symptoms. It is a validated self-assessment tool, originally developed by Bruera and colleagues to document the symptom burden in advanced palliative cancer patients (*Hui and Bruera*, 2017). It is used within oncology and helps identify patients unmet needs by systematically screening multiple symptoms. Over time the tool has been tested, revised, and translated into several languages. Changes have been made in symptom descriptions, as some patients struggled with the terminology and the use of numeric values (*Bergh et al.*, 2012). The revised version, ESAS-r, contains nine core symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, feeling of well-being, and shortness of breath. It also contains a slot for an optional tenth symptom. The time frame for ratings is specified as "now" (*Watanabe et al.*, 2011). While it originally used a VAS to score the intensity of symptoms, ESAS-r has shifted to NRS-11.

Studies have documented various results of the usefulness and validity of ESAS and ESAS-r, for both patients to share their symptoms and for HCPs to use this information in treatment and clinical decision-making. In a study comparing ESAS and ESAS-r with 160 palliative care patients, patients rated both versions as easy to understand and complete (*Watanabe et al.*, 2011). Even so, ESAS-r was rated significantly easier to use and was the preferred tool. A Norwegian study on the implementation of ESAS as a standardized tool for pain assessment among palliative patients, found that the tool allowed better assessment of patients and their complex conditions compared to simpler tools (*Torvik et al.*, 2014). HCPs reported that ESAS helped form a holistic view of the

patients' disease and experience, but they encountered difficulties in educating terminal patients on how to map their pain. This highlights the importance of introducing the patients to assessment tools in the early stages of the disease.

Other research have reported on the potential downsides of ESAS/ESAS-r. Research on the implementation of ESAS in a specialist palliative care unit, reported low completion rates of 20%, attributed to the staff's perception that it was too difficult for sick patients to complete. 35% of nursing staff also felt that ESAS was overly time-consuming for patients and staff and that it was not clinically significant or helpful. Nurses argued that the tool only gave a snapshot of the patient's well-being and an inaccurate representation of the patient's 24-hour symptom profile. Similar discoveries with ESAS-r were seen in a study by *Beddard-Huber et al.* (2015) where 75% (N = 3) of participating physicians claimed that ESAS-r did not enhance clinical assessment. 62% (N = 10) of nurses thought it was a burden to the participants. In contrast 60% of patients thought otherwise. *Torvik et al.* (2014) found that physicians were initially skeptical of the implementation of pain assessment tools like ESAS, as they believed it could lead to increased use of analgesics. HCPs' attitudes are decisive in the proper implementation and use of assessment tools, and their skepticism and beliefs do not always align with the experience of the patients. Other limitations of ESAS/ESAS-r are that they are unidimensional, some of the items like "well-being" are not well-defined, and their accuracy in reflecting longitudinal changes in patient symptoms relies on the frequency of administration and how accurately it is assessed (*Hui and Bruera*, 2017).

2.4 mHealth and Telehealth for pain/symptom management

The Internet of Things (IoT) has driven interest in a wide range of new health practices and technologies (*Kelly et al.*, 2020). One of which is *Mobile Health* (mHealth), defined by the World Health Organization as:

> medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, Personal Digital Assistants (PDAs), and other wireless devices

mHealth is a component of *eHealth*, electronic health, and has emerged due to rapid advances and the spread of mobile technologies and applications to address health priorities (*WHO*, 2011). It is often associated with the term *Telehealth*, which encompass "the provision of health-care services remotely by means of telecommunications technology" for instance through telephone, web-based methods, and mobile applications (*Goodman et al.*, 2022; *OED*, a). The rise and increasing accessibility of the Internet and mobile technologies offer new opportunities to provide affordable healthcare to a growing and aging society. It allows people to access health care where it is hard to acquire face-to-face interaction due to cost constraints, transportation requirements, and mobility (*Vardeh et al.*, 2013). Nonetheless, there are clear gaps between the scientific and commercial sides of mHealth, and several available procedures have yet to be subject to proper assessment and validation (*de la Vega and Miró*, 2014).

For pain monitoring, tools like electronic diaries, PDAs, internet interventions, text messaging, and mobile applications have materialized. *Vardeh et al.* (2013) have reviewed some of the scientific evidence of mobile technology for chronic pain man-

agement. Electronic diaries have shown promising results as opposed to paper diaries, concerning test reliability, validity measures, compliance, patient satisfaction, and even user-friendliness (*Marceau et al.*, 2007; *Morren et al.*, 2009; *Palermo et al.*, 2004). Other technologies for pain assessment and management, encompass web-based cognitive-behavioral therapy and peer-support programs, text messages promoting users to log their pain, and the utilization of machine learning and knowledge-based systems, that may assist HCPs in the decision-making process (*Argüello Prada*, 2020; *Vardeh et al.*, 2013). For instance, research within mHealth and multi-modal sensing has applied methods such as image processing of a facial expression, activity monitoring, bio-signals, and audio analysis of speech for the measurement and management of chronic pain (*Aung et al.*, 2016). Combining mobile data from both active sensing (e.g. self-reports), and passive sensing (e.g. activity tracking), may reveal new insights about the patients. While activity trackers on wearables and smartphones are widely available to the general public, systems that analyze small-scale behaviors like facial expressions, face significant challenges between what is feasible in laboratory settings and the limitations of the real world (*Aung et al.*, 2016).

2.4.1 Information and Communication Technologies (ICTs) in cancer and palliative care

The expected increase in cancer cases over the next years pushes the demand for capable HCPs. Research on the use of Information and Communication Technologies (ICTs) in cancer and palliative care is growing to address the barriers of supportive care by facilitating greater communication between patients and HCPs (*Aapro et al.*, 2020; *Allsop et al.*, 2015). This is often done through Electronic Patient-Reported Outcomes (ePROs).

Technology for cancer and palliative care

Goodman et al. (2022) have reviewed advanced cancer patients' engagement, frequency, amount, duration, and depth of use of different Telehealth approaches. They assess that patients with advanced cancer can successfully engage with Telehealth interventions of varying types. Tablet or smartphone interventions were associated with the highest levels of actual patient engagement compared to telephone, web-based, or other approaches. Smartphone interventions offer cost-efficient and accessible alternatives, even in rural and low-income populations. *Haque et al.* (2015) researched how technology can overcome the challenges of monitoring and assessing breast cancer patients in rural Bangladesh. Rural breast cancer patients are reluctant to visit health care centers, due to socio-cultural barriers, financial restrictions, and transportation hazards. One of the standard assessments of patients is for them to fill in daily ESAS. In practice, this was only done by the doctors, who reported insufficient time and lack of regular information from the patients. In response to these barriers, a phone-based eESAS was developed for patients to use at home. The implementation showed how eESAS positively impacted patients and doctors lives, by increasing the validity and reliability of data, and enabling doctors to study patient changes over time.

Digital solutions collecting ePROs in oncology show beneficial results for patients

regarding symptom reporting and management, reduced symptom distress and unplanned hospitalizations, as well as improved QoL and survival (*Aapro et al.*, 2020). Still, solutions must be mindful of the limitations of the population in question. *Hjermstad et al.* (2012) have studied the feasibility of computer-based symptom assessment with 965 advanced cancer patients. They found that predictive factors of non-completion were related to higher age, lower performance status, and more pain. The need for assistance was also predicted by higher age, lower performance as well as lower education level. 50% of participants had little to no experience with computers. Completion rates were nevertheless high, 94.9%, in spite of the lengthy assessment. About half preferred the computerized assessment over the paper if given the choice. Altogether, computerized symptom assessment was found to be a feasible with advanced cancer patients from different countries, languages, and places of care.

In terms of QoL, a review of 38 digital health solutions remotely collecting ePROs for supportive care, showed that solutions that included patient self-management displayed promising results of improvement of QoL and reassurance (*Aapro et al.*, 2020). One of the featured solutions is NOONA, a digital ePRO platform for clinical use. It enables cancer patients to self-report symptoms and side effects of cancer treatment from home, via a computer or other smart devices (*Peltola et al.*, 2021). *Peltola et al.* (2021) have studied the use of NOONA among 44 cancer patients and 17 HCPs. 93% of patients and 88% of HCPs found NOONA easy to use, and the majority thought it was reliable and would recommend it to other patients or colleagues.

Drivers and barriers for the adoption of digital health solutions must be addressed in regards to patients and HCPs. *Aapro et al.* (2020) identified patients' drivers to be improved communication with HCPs, patient empowerment, and the convenience of real-time reporting of symptoms. Barriers encompassed limited usefulness, and lack of clarity of the language used. Both patients and HCPs believed that the usability and usefulness of the tools were important, while the need for specific training and issues with the technology or connectivity were seen as barriers.

Technology and cancer survivors

mHelath and Telehealth interventions for self-management and reflection may also support cancer survivors when returning to usual roles and routines. Cancer survivors face their own struggles relating to persisting symptoms and late effects of treatment, influencing their social and psychological well-being (*Boland et al.*, 2017). The transition from treatment to aftercare requires changes in the patient's self-care, as well as coordination with continued medical care, which is a demanding process (*Larson et al.*, 2020). In a systematic review of six self-management interventions for cancer survivors, two of the studies that showed significant post-intervention results were both web-based interventions of long duration (*Boland et al.*, 2017). Support for the effect of Telehealth on the QoL of cancer survivors compared to usual care is seen in several studies (*Larson et al.*, 2020).

Cancer survivors often experience bodily changes and fear of recurrence, and there is a need for tools to help articulate and understand one's story of illness in order to improve self-care after treatment (*Flobak et al.*, 2021). The same need and emphasis on psychosocial support, e.g. by conveying and sharing experiences and seeing others struggle with the similar effects of illness, are as critical in cancer management as in

general pain management. *Flobak et al.* (2021) explored the use of audiovisual narratives for an online intervention, to support recognition and reflection of cancer journeys in patients recovering from gynecological cancer. Narratives were made through an experienced-centered design process with gynecological cancer survivors, on their experiences of everyday life after cancer treatment. Ten participants, who previously had undergone treatment, participated in the design process or evaluation. The narratives were deemed realistic, credible, relatable, provocative, and meaningful.

2.4.2 Pain applications

The latest trend within mHealth is the emergence of downloadable health-oriented mobile applications with the purpose of "... monitoring and acquiring information about a specific condition" (*Vardeh et al.*, 2013). These applications allow for EMA, are usually designed for non-clinical use, and can often operate independently of an internet connection. The downsides of these applications are that few of them adhere to established guidelines and scientifically proven concepts of health monitoring and assessment (*Vardeh et al.*, 2013). They are also readily available for anyone to use without the guidance of health professionals, and it is often unclear whom to contact and hold responsible if something goes wrong (*de la Vega and Miró*, 2014). Using smartphones for EMA, although convenient, may also be disruptive and distract from the users' everyday life. The action of pulling the phone out of your pocket, unlocking it and using it, can be more time consuming than alternative measures (*Hernandez et al.*, 2016; *Rodríguez et al.*, 2016).

The insufficient evidence to conclude the efficacy of app intervention for pain is supported by *Portelli and Eldred* (2016). They reviewed 195 applications from the Android and iPhone market, by employing an evidence-based checklist to rate their quality and adherence to best practices. They found that few applications were developed by individuals with experience in the delivery of health behavior change interventions, often laypeople or software developers. The apps also lacked theoretical content and basis for facilitating self-management of behavior change. As pain is subjective, a generic application will often fall short if patients must adapt their experiences of pain to something generalizable (*Fyhn and Buur*, 2020). *Portelli and Eldred* (2016) argue that the lack of regulatory body and experts overseeing the selling of smartphone applications and their content, can negatively affect users as relying on unprofessional advice may cause worsening pain symptoms. *Ali et al.* (2021) document similar results through a systematic review of digital smartphone manikins for the self-reporting of pain. They found that for all applications included in the final analysis (N = 28), it was unclear whether they had been tested or if end-users were involved in the development. This suggests that there is a gap between applications that have been investigated in research studies and those publicly available.

Some research on commercially available applications exists. *Vanderboom et al.* (2014) studied the feasibility of technology-enhanced symptom monitoring for patients (N = 20) with fibromyalgia through an iPod touch and the commercial pain/symptom monitoring application My Pain Diary. However, the study also engaged nurses who responded to participants' symptom reports daily. Participants found it easy to monitor their symptoms through the iPod, and they valued the use of a monitoring device to

track progress over time and help balance attention to symptoms. They also appreciated the interaction with nurses, which helped reinforce self-management.

An application with a scientific basis is Painometer, a mobile application for the assessment of momentary pain intensity (*de la Vega et al.*, 2014). It includes four different pain scales: FPS-r, NRS-11, VAS, and the Colored Analogue Scale. The application has shown good results in terms of usability and acceptance when used by healthcare professionals ($N = 24$) and nonprofessionals (children, adolescents, and young adults ($N = 30$)). The majority of health care professionals preferred the application over the paper versions, and it was described as practical, useful, funny, and attractive. *Sánchez-Rodríguez et al.* (2015) have investigated the psychometric properties and the validity of the scales in Painometer by comparing them to their traditional, verbal or paper counterparts. For all scales, participants ($N = 180$) were asked to report the maximum intensity of their most frequent pain in the last 3 months. The results show that scores reported with Painometer were concordant with the paper scales and valid. 79% of participants also preferred the electronic version.

Adams et al. (2017) addresses some of the issues concerning health-oriented applications. They explored how chronic pain patients prefer to self-assess their pain levels on smartphones, using different scales, including a modified VAS and the Sydney Animated Facial Expression Scale. Participants were influenced by design features and found playful interactions and aesthetic interfaces to be highly enjoyable and motivating over extended periods. Response rates were generally high and response burden low. Participants displayed strong and differing preferences toward the scales. Some had trouble relating to the faces scale, considering it to be inaccurate for pain assessment. They preferred numeric scales as numbers are familiar parts of everyday life. Others were opposite, and experienced difficulties in quantifying abstract experiences. The research argues that there is no one-size-fits-all and that pain tools must accommodate the different users needs to ensure that they feel understood and maintain their motivation and compliance over time. Some of the participants expressed that using the application provided an outlet, that externalized and even eased pain perceptions. *Adams et al.* (2017) suggest to further look at the area of tangible user interfaces and how they can support natural interactions and unobtrusive logging of pain.

2.4.3 New challenges and ethical considerations

Despite mobile technologies and other ICTs bringing forth benefits for both patients and the HCPs, they also highlight new challenges. Health systems must adhere to clinical guidelines, and the implementation, supply, and use of IoT devices in health care services rely on a clear and robust code of practice for the management of data, privacy, confidentiality, and cyber security (*Kelly et al.*, 2020). Data containing patients medical information is especially sensitive and must be properly secured, and concerns about conflicts of interest and biases must be taken seriously (*de la Vega and Miró*, 2014). Other considerations are cost-effectiveness, how to properly educate patients and HCPs on the use of new tools, and how more general solutions can cater to individual patients' needs (*Aapro et al.*, 2020). When implementing technology in pain, cancer, and other populations, that often experience reduced functioning, caution must be taken to lower the respondent burden and prevent low compliance and need of assis-

tance (*Hjermstad et al.*, 2012). Emphasis must be placed on the usability of the health interventions, particularly on user satisfaction and engagement, which is important to promote recurrent and frequent use, and lead to better-intended health outcomes for patients (*Goodman et al.*, 2022).

2.5 Affective and tangible interaction

An integral part of life is bodily experiences as our bodies are always there with us, inseparable from our thinking, emotions, and understanding of the world (*Höök*, 2013). *Affective interaction* builds on this notion, aiming to design systems that spur users' emotional experiences through interaction. *Tangible interaction* in turn, encompasses

> user interfaces and interaction approaches that emphasize the tangibility and materiality of the interface, physical embodiment of data, whole-body interaction and the embedding of the interface and the users' interaction in real spaces and contexts (*Hornecker*, n.d.).

Tangible and affective interaction are relevant areas of research with regards to the physical body of Grasp and the intentional action of squeezing it. Existing studies have reported the potential of pain relief by externalizing pain experiences or distracting from them through squeezing (*Adams et al.*, 2018; *Tumakaka et al.*, 2020).

Throughout the Human-Computer Interaction (HCI) community, products and artifacts have been designed and researched, combining the ideas of affective and tangible interaction. The rise of technologies, like sensors and actuators, enables users to interact with artifacts in new ways by engaging their whole bodies (*Höök*, 2013). One example is *CheekTouch* by *Park et al.* (2012), a bidirectional, affective audio-tactile communication technique, that supports emotional communication over distance. CheekTouch allows users to share emotions nonverbally during phone calls. The sender applies multi-finger touch on her phone, which in real-time is transmitted to the receiver's phone in the form of tactile feedback felt on the receiver's cheek. It has been found to effectively support audio-tactile communication in various ways by emphasizing emotions or words, delivering information, and encouraging playfulness.

2.5.1 Affective interaction

During the 90s the traditional cartesian mind-body dualism was questioned, as one came to realize that emotional experiences can be experienced by our whole bodies, not just our minds and brain, but also through facial expressions or hormone changes (*Höök*, n.d.). Bodily movements and emotion processes are tightly intertwined and can generate one another. Emotions are further constructed and altered in dialogue with others and our cultural and social surroundings. Smiles are said to be contagious, and studies provide evidence that forced postures and facial expressions can evoke corresponding emotional responses (*Flack Jr et al.*, 1999). *Flack Jr et al.* (1999) examined the effects on participants mimicking expressions and postures of different emotions. They found that participants indeed felt the associated emotional responses when enacting specific expressions, postures, or combinations of both. Angry facial expressions, angry body postures, or a combination of the two increased the participants' self-rated

feeling of anger. By considering bodily interactions and emotions when creating products and artifacts, we can facilitate new user experiences. Pain is closely related to emotions where there is an overlap in conceptual and neuroanatomical spaces (*Gilam et al.*, 2020). Fear of an external stimulus can inhibit pain, and external noxious stimuli may activate defensive behaviors to help us cope with the experience (*Lumley et al.*, 2011). Additionally, greater pain is related to emotional stress, and limited emotional awareness, expression, and processing. Conversely, positive emotional states are generally found to reduce pain.

Turner (2017) describes affect as a variety of psychological states including emotions, feelings, impressions, and moods, where emotions are the most relevant in a user experience. Two approaches to emotion and technology within HCI are Affective Computing and Affective Interaction (*Höök*, n.d.). Affective Computing emerged to meet the challenges of emotions and technology, aiming to develop systems and devices that can recognize, interpret, process and simulate a range of human emotions (*Turner*, 2017). This theoretical perspective builds on cognitivist models of emotion with roots in neurology, medicine, and psychology (*Höök*, n.d.). Affective computing devices for the logging of affective states, often aim to be unobtrusive by utilizing bio-sensor or other passive and automatic sensing techniques (*Krøger et al.*, 2015). Affective Interaction came about as a counter-reaction to Affective Computing. Here systems do not aim to recognize or replicate users' emotional states, nor to minimize obtrusiveness. The goal is to support people in understanding and experiencing their own emotions, by making emotional experiences available for reflection (*Höök*, n.d.). It regards emotion as processes constructed in interaction. Whereas one cannot directly design an emotional experience, one can design technology that through use and physical interaction can evoke experiences and feelings. An example is the Affective Diary by *Ståhl et al.* (2009). This digital diary allows the user to record bodily memorabilia, i.e. data from body sensors, notes, and mobile media from the users phone. Data from sensors are visualized on a timeline through different anthropomorphic figures, where their posture reflects how much the user has been moving throughout the day, and their color represents the users arousal measured by galvanic skin response. Photos, Bluetooth devices, and SMSs sent and received are also represented along the same timeline, to set the social context and help the user infer meaning from the interactions.

2.5.2 Tangible interaction

Tangible Interaction is an interdisciplinary area concerned with interfaces and systems that in some way are physically embodied, whether that be a small object we can grasp or bigger objects in larger spaces in which we use our bodies to navigate and move around in (*Hornecker*, n.d.). It concerns interaction with *Tangibles* that can be described as "interfaces, where computational power is embedded in everyday artifacts or customized objects, that can be wirelessly networked or linked to various forms of digital representation" (*Price et al.*, 2013). Tangible technologies are flexible when it comes to design, considering the objects themselves, the actions they entail, their digital information, and what context and role they take on or represent in the environment. The field is becoming increasingly diverse, but the collective focus lies on the design of the interaction and how users would use the system, rather than the visible inter-

face alone (*Hornecker*, n.d.). Physical forms of action and manipulation of tangibles allow us to build on our everyday interaction and experiences of the world (*Price et al.*, 2013).

Tangible Interaction first gained attention through the work on *Tangible User Interfaces* (TUI) that emerged as an alternative to already established *Graphical User Interfaces* (GUI) (*Hornecker*, n.d.). The work of *Fitzmaurice et al.* (1995) and their exploration of graspable bricks as input devices, have been especially important, laying the foundation of what they called Graspable User Interfaces. *Fitzmaurice et al.* (1995) argue that there are several benefits to graspable user interaction such as taking advantage of our spatial reasoning skills, affording collaborative use, externalizing internal computer representations, and facilitating interactions through physical artifacts making elements more "direct" and "manipulable".

Everyday usage of the word tangible simply denotes something "capable of being touched; affecting the sense of touch; touchable." (*OED*, b). *Fyhn and Buur* (2020), as mentioned previously, studied the potential of chronic pain scales in tangible materials. They investigated how chronic pain patients can express their pain experiences through material metaphors like dolls, clay, and pictures. The tools used are not considered Tangibles, but they are very much tangible and invite exploration, expression, and meaning through physical manipulation and interaction. Participants were able to successfully physicalize their pain by engaging themselves in the materials, and for some, it enabled them to open up and talk about their pain to their environment. These insights may also transfer to tangible pain reporting tools. The demand for inconspicuous and convenient input methods for self-reporting has driven research on a variety of new and tangible devices, some of which are presented in the following section (*van Berkel et al.*, 2022).

Tangible and affective devices for self-reporting, regulation, and management

Within mental health and psychology, several interesting studies on the use of tangible or affective devices for self-reporting, regulation, and management have prevailed. *Roquet et al.* (2022) explored the use of a tangible intervention for in situ, embodied support of emotion regulation. The study employed the commercially available *Purrble*, a small technology-enabled object in the form of a plush animal, originally developed for emotion regulation among children. Purrble provides sound and vibration feedback. It embodies the emotion regulation process by showing signs of anxiety, and calms down when being stroked by humans. The majority of participants had a positive experience, finding Purruble easy to use. Its physicality and embodied interactions had a soothing effect on many. Participants found Purrble useful in down-regulating heightened emotions, i.e. calming down when feeling anxious, stressed, and overwhelmed, and distract from negative emotional triggers. For some, the tool became a compassionate emotional companion, by countering loneliness and fostering conversations about emotions, and encouraged nurturing behavior and self-compassion. Another example from mental health is the work by *Ferrario et al.* (2017) who studied how technology and action can support reflections for mental health management through the approach of *intentive computing*. The term was originally coined by *Simm et al.* (2016) and is described as the study of the use of systems triggered by users' intentive actions, that is " requiring the user to consciously and knowingly trigger a system for example, push a

button or make a certain gesture." It is similar, and overlapping with affective interaction, but with a clear focus on intentionality, drawing a parallel to the concept of Grasp. *Ferrario et al.* (2017) extends this concept by emphasizing reflection in action, and the importance of sense-making. They developed a mobile platform, in which the user only needs to click a button to log a mood. This is both efficient and of a low cognitive burden. The click triggers the location and time-stamp to be saved, and the platform provides visualizations of the interaction for later reflection. Through their investigations on anxiety in autism, it was revealed that conscious interactions can function as memory anchors irrespective of the content captured and even before visualizations, as well as facilitate real-time anxiety relief.

The field of tangible interaction also spans work on *fidget tools*, tangible objects that are not a part of one's body, in which one can *fidget* or interact with and modify by repeated hand movement (*da Câmara et al.*, 2018; *Karlesky and Isbister*, 2016). This is often done without a specific purpose. *Karlesky and Isbister* (2016) investigated the design space for embodied *self-regulation* through *fidget widgets* or "objects manipulated with the hands alongside daily deskwork", focusing on the interactions with the space around computers through the objects it contains. They define self-regulation as

> a self-initiated process that consciously or subconsciously redirects a spontaneous flow of thoughts and feelings to increase, maintain or decrease internal states including but not limited to: anxiety, focus, creativity, calm, and motivation.

The study employed an online blog, a Tumblr page, encouraging people to submit photos and videos of their fidget tools. Submitted items ranged from paperclips, rubber bands, and stress balls, to cellophane tape, walnut shells, and headphones. Participants exhibited diverse interactions with a variety of materials and textures. Analysis of the content revealed that individuals have a "strong, specific and idiosyncratic preference" for what items they interact with while working, and it suggests that self-regulation towards achieving focus, calmness, and creativity occurs. Similar findings have been observed also in children. *da Câmara et al.* (2018) identified, through their research on children's fidget object preferences, five reasons why children fidget. Among others, to perform cognitive tasks, regulate emotions in class, and dispel excess energy. They also found that children favored different interactions, depending on their emotional states. Children stated a preference for soft materials, and they preferred fidget items with inherent squeezing interactions when they were angry. When bored, items enabling clicking, pressing or tapping were preferred.

A rather direct example of a tangible pain scale to engage patients' self-logging is *Painpad* by *Price et al.* (2018). It was designed to meet the challenges of nurses regularly collecting scheduled pain readings of in-hospital patients. Painpad consists of a 3D-printed keypad with buttons from 0 to 10, i.e. a tangible NRS-11. It prompts the user to report their pain through scheduled audio and visual reminders. Through hospital-based field studies with patients recovering from ambulatory surgery, Painpad showed improved compliance and frequency of pain logging. Analysis suggests that the self-logged scores are possibly more faithful to patients experienced pain than corresponding scores reported to nurses. Patients reported that Painpad made it easy to remember and log their pain. They also exhibited individual preferences and needs. Some had a hard time hearing the audio signals, whereas others experienced the prompts as

noisy and embarrassing. When compared to a tablet-interface, Painpad was the preferred tool to log pain, but the appearance of the tablet-interface was rated higher. Pain and symptom devices should adhere to patients individual needs and preferences, and special considerations must be made when designing for in-hospital use. This seems to be a reoccurring theme of several of the aforementioned studies.

One last category of tangible sampling devices for EMA is that of *wearbles*, explained in short as electronic devices that can be worn, often on the wrist (*Hernandez et al.*, 2016). *Hernandez et al.* (2016) have compared head- and wrist-worn wearables for EMA to that of smartphones, and found significant differences in response time. There were no significant differences in the time (N = 15) spent from when a prompt was triggered until the user submitted an interaction. However, the time it took for users to start interacting with the device after receiving the first trigger was significant. Here the phone took the longest as it had to be fetched from a pocket. A longer response time can reflect how disruptive a task is, and mobile interfaces may increase the threshold for making entries (*Krøger et al.*, 2015). *Rodríguez et al.* (2016) presents a comparative study of one tangible and one mobile application for self-reporting of pain in everyday life. The study found that 67% of the users preferred the wearable device, a bracelet, over the mobile application, notwithstanding it meant having to carry an extra device. Both the application and the bracelet used a VRS with three levels of intensity, indicated by three different colored buttons. Participants considered the bracelet easy to use, requiring low cognitive load, and better for pain-logging in the moment as it did not require one to turn on a cell phone, or open the app. It was also suggested that the two prototypes could complement each other as they are appropriate in different situations. *Rodríguez et al.* (2016) reported that devices for pain reporting must be made specific to this purpose and be aesthetically pleasing.

The concept of grasping and squeezing as an input-method

As seen in early work on tangible interaction like the one by *Fitzmaurice et al.* (1995), the action of grasping objects is a central idea. Grasping is an inherent human action as our hands naturally and flexibly "reach for objects, grasp and lift them, manipulate them and use them to act on other objects", bridging sensorimotor and cognitive functions (*Castiello*, 2005). *Feix et al.* (2016) defines a grasp as "every static hand posture with which an object can be held securely with one hand, irrespective of the hand orientation" and has identified 33 different grasp types. Objects can be grasped in multiple ways depending on their properties, including size, material, weight, and how fragile they are (*Castiello*, 2005). Previously attached meanings (imagine a coffee cup compared to a neutral wooden block) to an object, and what we intend to do with it, may also modulate how we grasp it. Depending on the level of required granularity one may simply distinguish between *power grip* in which the "fingers are flexed to form a claim against the palm" or *precision grip*, characterized by "opposition of the thumb to on or more of the other fingers"(*Castiello*, 2005). Grasp uses the latter.

Studies exist on the use of grasping and squeezing as input methods. One example is the work by *Simm et al.* (2014) on *Clasp*, a tactile tool for anxiety management, communication, and peer support for adults with high functioning autism. It consists of a smartphone application and a tactile ball connected via Bluetooth. The ball is a *blobo*, a hard off-the-shelf squeeze sensor. When the ball is squeezed, time, location, and trig-

gers of anxiety are recorded, and the phone provides appropriate feedback depending on the users personally defined thresholds. Adults with autism noted that non-verbal communication would be most useful when expressing emotions while anxious. Hence, responses to squeezes include sending an SMS to a friend, posting on a social network service, or a user-defined distraction without requiring user intervention. The participants viewed anxiety tracking as useful and were open to the idea of an external device. At the same time, they did not like the feel of the ball as they wished it was softer or "with squeeziness". *Chong et al.* (2014) have taken the ideas of squeezing blobo into a different context in their work on the *SquezeDiary*, a mobile diary application consisting of an app, based on the one from *Simm et al.* (2014), and a blobo sensor (*Chong et al.*, 2014). The idea is to let users swiftly log daily events or experiences as they go about their life, and later reflect upon them.

A couple of studies exist on the use of tangible interaction and squeeze duration to distract from or log pain. *Tumakaka et al.* (2020) have researched what effect distracting children with a squishy object during intravenous catheter insertion can have on pain perception. 50 children of age 3-15 were assigned either to the control group, that received the standard intervention, or the intervention group, where they were provided with a squishy ball to squeeze during the procedure. Pain was measured right after the procedure using the Faces Pain Scale or an NRS, for children above 8 years old. A significant difference in pain scores between the intervention and the control group was observed. Children in the intervention group reported pain scores of non to moderate levels. In contrast, children in the control group reported pain from moderate to severe. The results indicate that distraction by squeezing effectively reduced the pain in children compared to the standard intervention.

van Berkel et al. (2022) have investigated and compared the accuracy and resolution of six different techniques for tangible participant input including different sliders, joysticks, knobs, and squeezing. Their lab study ($N = 20$) indicates that accuracy was highest using sliders and lowest using squeeze-based inputs. It did not consider the affective dimensions of different devices. Six wireless, one-hand operated devices with similar appearance, but different input methods were designed. Participants used all devices, and for each one they tried to input randomized target values between 0-100, while holding the device out of sight. When they believed the target value was reached, an on-device confirmation button was pushed. The squeeze input revealed a larger offset in the input range compared to the other methods for values above 40, indicating that offsets are related to the strength of the squeeze. It was also the least favored device, but one participant commented that the pressure device gave him the most control as he could use his entire hand. Haptic feedback seemed to help participants assess the input range. For example, the joystick could be pushed in two directions but returned to a neutral or "middle" position once pressure was removed. Participants used this as an anchor when aiming for target values.

Another study using *Keppi*, a pressure-based, tangible and portable user interface in the shape of a squeezable stick, found that participants were able to map squeeze pressure to pain levels and reliably report low, medium, and high pain, even without visual feedback (*Adams et al.*, 2018). In contrast to *van Berkel et al.* (2022), participants using Keppi perceived less pressure control at lower pressure levels. However, the studies are not directly comparable as Keppi uses a different scale, does not require the user to confirm the input by pushing a button, and is made of a compressible material. Partici-

pants were given different versions of Keppi in which they were asked to perform tasks such as reporting the highest possible value (hardest squeeze), and tracing an animation of a red circle by squeezing according to its movement. The tasks were performed both with and without visual feedback of the pressure they were exerting. Keppi is inspired by the action of squeezing a stress ball, and the way one may reach for the hand of a loved one or a nearby object to grasp in moments of pain. The majority of participants thought that squeezing was a natural interaction. They also believed that the mapping from squeeze intensity to pain level made sense. Some participants suggested that squeezing Keppi could help externalize negative pain perceptions. Others reported that squeeze pressure was too subjective, and they suggested using squeeze duration, or adding buttons to be used in situations where squeezing is not suitable. It was also suggested to include on-device feedback.

Using pressure to represent pain intensity has also been explored by *Schaffner et al.* (2012) with Painmouse, a tangible hand-held device that measures the pressure exerted when grasping. It takes the shape of a 13 cm long dumbbell, and enables users to express pain intuitively and in real-time by squeezing it. Two studies were conducted to assess the acceptance and validity of Painmouse. In the first, a test and a re-test, with 16 healthy, male participants exposed to varying heat stimuli were conducted. Participants' individual pain thresholds were measured, and from these four levels of pain were calculated. Each participant completed two sessions of 15 individual pain stimuli, where one session was rated via a VAS and one using Painmouse. Participants were able to distinguish four different pain levels of pain using both tools. PM was rated slightly higher in terms of intuitiveness than the VAS, but both were rated high in accuracy. For the second study 13 female and male participants with leg ulcers used PM during dressing changes. The participants were asked to squeeze PM according to the pain felt during different stages of the procedure. In-between each predefined stage the participants were asked to fill out a NRS-11. Painmouse was found suitable for enabling pain assessment, even under difficult clinical circumstances.

Whereas tangibles have brought new possibilities on how to measure pain, their dependence on a physical body, often novel hardware, as well as software, implies new challenges concerning costs, size/weight, portability, robustness, usability, and accessibility, and how one would best bring such tools to the masses without disregarding personal preferences. Several existing devices also lack instant feedback mechanisms for users to confirm their input which can lead to discrepancies between users' intended input and the actual recorded data *van Berkel et al.* (2022). *Adams et al.* (2018) found that such devices should be inconspicuous and easily accessible throughout the day, preferably in the form of wearables. One of the main principles of EMA tools is to "minimally disrupt daily activity while collecting as much information as possible" (*Hernandez et al.*, 2016). Careful considerations must therefore be made when designing notifications prompting users to log their experiences, as well as the complexity and length of prompts, tasks and questions to be answered as they go about their day.

2.6 Summary

As seen in this chapter, there is an abundance of research on pain and symptom assessment tools. Even though numeric and verbal pain scales have proven useful and

practical in clinical settings, there is still an ongoing debate on whether this approach truly reflects the participants' subjective experiences, and if such data are sufficient in painting a holistic view of patients' overall conditions. Although cheap and in most cases easy to administer, traditional pain scales face challenges and they are often used retrospectively of pain events. With technological advancement, new methods for pain logging and assessment have emerged from digital diaries to mobile applications. The use of smartphones can eliminate some of the shortcomings of the traditional scales. Pain applications allow in situ pain logging regardless of physical location. Yet, the action of bringing your phone out of your pocket and unlocking it may be disruptive to everyday activities. Research within mHealth is promising, but the gap between publicly available health applications and those that have been assed through research, must be addressed. Others have studied the use of different wearables devices may provide even less disruptive forms of pain-logging.

Lastly, some research on more unconventional approaches to pain logging and assessment has grown forth. Inspired by tangible and affective interaction, researchers have studied the potential of handheld, physical devices, looking not only at pain logging but also at the experiences such interactions may evoke. This thesis has continued to build on the tangible approach to pain logging and explore this new area further.

Chapter 3

Grasp

Grasp has been developed over the course of several years of ideation and prototyping. This chapter includes a summary of some of the earlier research on what is now known as Grasp. It then presents the two Grasp versions used in this project, Grasp version 2.0 and Grasp Pilot Edition.

3.1 Development and research on Grasp

Krøger et al. (2015) have explored the logging and visualization of affective interaction in mental health therapy, through what was then, a platform under development. The platform consists of a portable stone-like object, and a visualization application on an iPad. The study focused on the design and evaluation of the latter, and how it can be applied in therapeutic settings to support dialogue between patients and therapists. Visualizations should provide information about the patients' development, and a quick overview of their affect over a period of time. To illustrate affective states, visualizations are typically accomplished through colors, emoticons, pictures, and graphs. A high-fidelity prototype was made and formatively tested through usability testing. It included a day and month view, and two month comparisons of data. The test revealed that despite potential, new iteration of design and evaluation was needed.

The paper "Designing for Tangible Affective Interaction" by *Guribye et al.* (2016) addresses the challenges of designing for in situ tangible affective interaction, in the context of mental health care. They present the development and evaluation of the Grasp platform through a user-centered research through design process. Users and domain experts were involved throughout the process. From a focus group, several requirements were formalized. For example, a functional requirement was that the device should be able to transfer data to another device for visualization. Non-functional requirements stated that the device must be robust and easy to maintain. Additionally, regarding interaction and material, the device should invite squeezing, be handheld, and be inconspicuous. The article further identifies four interactional modes for pervasive affective sensing: in situ intentional, retrospective, automatic and reconstructive. Pervasive affective sensing encompasses "the process of monitoring and translating various indicators of emotional states into meaningful information". These modes vary across two dimensions depending on whether the user is *active* or *passive* in the interaction process, and whether the registration of the users affective state is performed

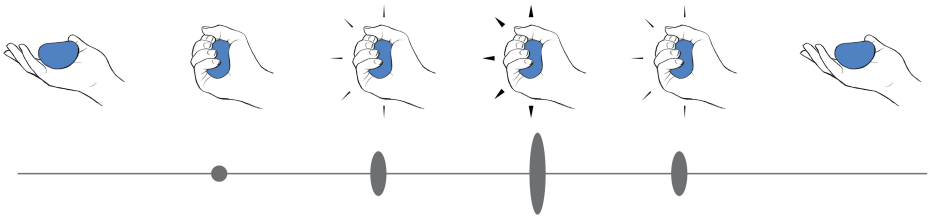
synchronously or *asynchronously* with the experience. Grasp was created with the in situ, intentional mode in mind, allowing the users to effortlessly and intentionally capture and express affect in the moment. The envisioned use case was a therapist-patient context where Grasp could be used as a transitional object, to alleviate recall bias, encourage conversation, and function as extended memory. The small field trial revealed several potential use cases of Grasp, and participants were overall positive about its design and usability.

A work-in-progress by *Guribye and Gjøsæter* (2018) applied a modified version of the Grasp platform, Grasp Live, to the unconventional setting of a dentist appointment. Grasp Live is a "haptic interaction technology" consisting of the tangible Grasp, live visualizations of squeezes on a smartphone, and vibrotactile feedback on a smartwatch. Some people dread going to the dentist. This is often due to the fear of potential pain and discomfort that cannot be easily communicated during an examination. The study explored how Grasp Live can be used to support meaningful communication between the patient and the dentist, potentially fostering an empathic relationship and helping ease the patient's distress during appointments. A small field trial in the form of a dental examination was performed. A patient suffering from mild dental anxiety held Grasp in one hand, and the dentist wore the smartwatch. When Grasp was squeezed, live visualizations were displayed on the smartphone mounted above the patient. Simultaneously, the watch notified the dentist through appropriate haptic feedback. The feedback helped communicate the patient's pain, and the exploration shows that there is potential in studying this form of communication further. However, the patient and dentist should agree upon the meaning of different interactions and what actions they should entail before the procedure.

3.2 The general idea of Grasp

The following figure, Figure 3.1, shows a simplified illustration of the overall idea of Grasp for reference.

Figure 3.1: Simplified illustration of the relationship between Grasp interactions and data visualisations. Grasp (2021b)



When Grasp is squeezed the time and duration of the interaction are logged. The tool is event-contingent, i.e. used when the user is experiencing a specific event. The data are automatically stored, and can later be transferred via Bluetooth to a mobile

application and web interface. After uploading data to the software, interactions are automatically scored on a 0-10 scale, where 0 is no squeeze at all. If needed, the score can be manually adjusted in the interface. Data are also categorized into either *low, medium,* or *high,* and presented visually on the interface through circles, graphs, and charts. The categorizations are general, and the user may decide how visualizations should be interpreted. The user can also supply additional information to the data points such as annotations, sentiments, or labels like "pain", "lack of appetite", "nausea", whatever the user wishes.

3.2.1 Grasp scoring and interface

The current calculation of a squeeze score follows the formula $(averagepower * duration)/100 = score$. Thus, squeeze pressure is also recorded. However, at the time of our studies, individual users' grip force can not be calibrated, and *average power* goes to max (0-250) quickly when squeezed. Therefore, *duration* measured in seconds, is the decisive factor used in the pilot study. That being said, strength and duration are somewhat interrelated. Just imagine squeezing a compressible stress ball and the nuances between a short and weak squeeze or a short and hard squeeze. Table 3.1 illustrates the relationship between squeeze duration, automatically calculated squeeze score, and category. The same relationship can be seen in Figure 3.2. This is a collection of screenshots from the web interface with a visual representation of squeezes. The image contains six individual squeezes of increasing duration, represented by increasingly larger circles and higher scores.

Table 3.1: Overview of automatic score and category based on squeeze duration.

Duration in seconds	Automatic score	Automatic category
0	0	N/A
1	2	Low
2	5	Medium
3	7	Medium
4	9	Hard
>4	10	Hard

3.2.2 Grasp versions

Grasp version 2.0

In the pilot study Grasp version 2.0 , Grasp Insights application version 1.3.0, and the web interface version as of January 17th, 2022, were used. Figure 3.3 shows an image of the Grasp version used in the pilot study, to the left, and the one that was developed for the clinical trial, to the right.

Version 2.0 was tested before the pilot to ensure that apparent flaws and problems were identified. I carried it with me in my pocket for two weeks during my school and work days, squeezing it now and then to confirm that it was working properly. One

issue noticed was shrinkage in the internal padding over time. This made Grasp feel hollow and the pressure sensor was no longer properly held in place. The outer silicone was also somewhat sticky due to a production error. Although Grasp was designed to be held across your palm leaning against the base of the thumb, as seen in the simplified Figure 3.1, the sensor would sometimes fail to track interaction when held this way. A plausible explanation is the material shrinkage. To ensure that all participants in the pilot could correctly exert pressure on the sensor, and thereby produce data, they were carefully instructed to squeeze the Grasp by holding it vertically. See chapter 5 for further details.

Figure 3.2: Screenshot from web interface showing the visualizations of different squeezes made on January 18th, 2022. When the user clicks on a circle an additional window pops up with information on squeeze duration and score, in this case, pain *score. Circles grow increasingly larger with longer squeeze duration.*

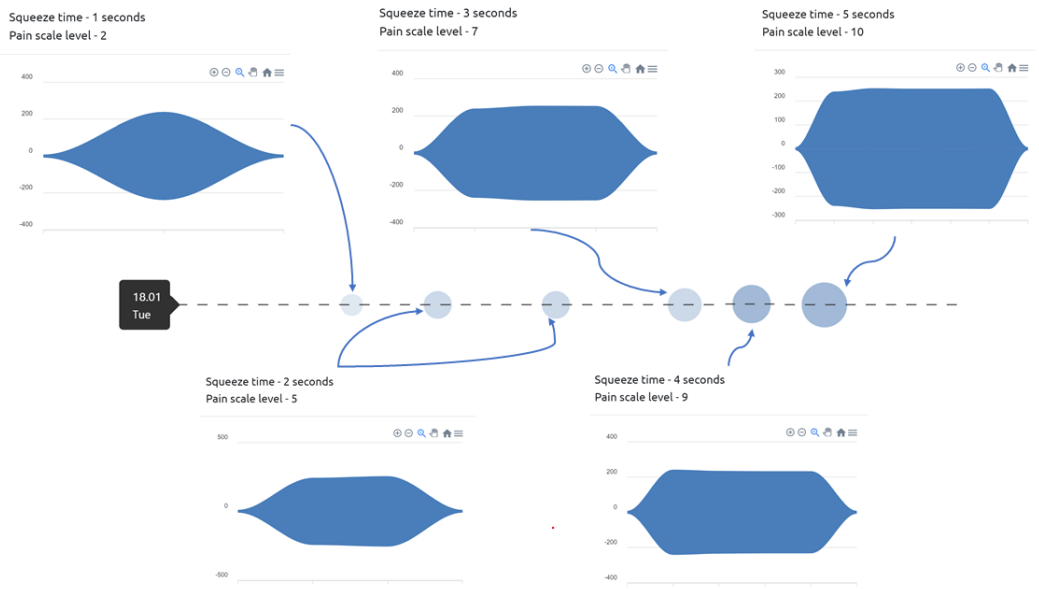


Figure 3.3: Grasp Version 2.0 and Grasp Pilot Edition.

Grasp Pilot Edition

For the clinical trial, Grasp Pilot Edition was created. Changes were made both to the hardware, changes in material and solving of shrinkage problem, and software, compared to its predecessor. Grasp Pilot Edition is also slightly smaller than Grasp Version 2.0, as can be seen in the side-by-side comparison in Figure 3.3. One of the major changes in software was to provide a digital version of ESAS-r. Here nurses could input the patients' ESAS-r ratings, which were then visualized as a small circle along the same timeline as squeeze observations, see Figure 3.4. ESAS-r data were also presented as a line graph to easier illustrate changes in symptoms.

Figure 3.4: Grasp Insights displaying real patient data. The blue circles of varying size and shade represent squeeze interactions. The green circle with an icon represents an annotation made by a nurse. Finally, the blue and red circles with a small icon indicate that an ESAS-r has been filled out (blue), or has been skipped (red).

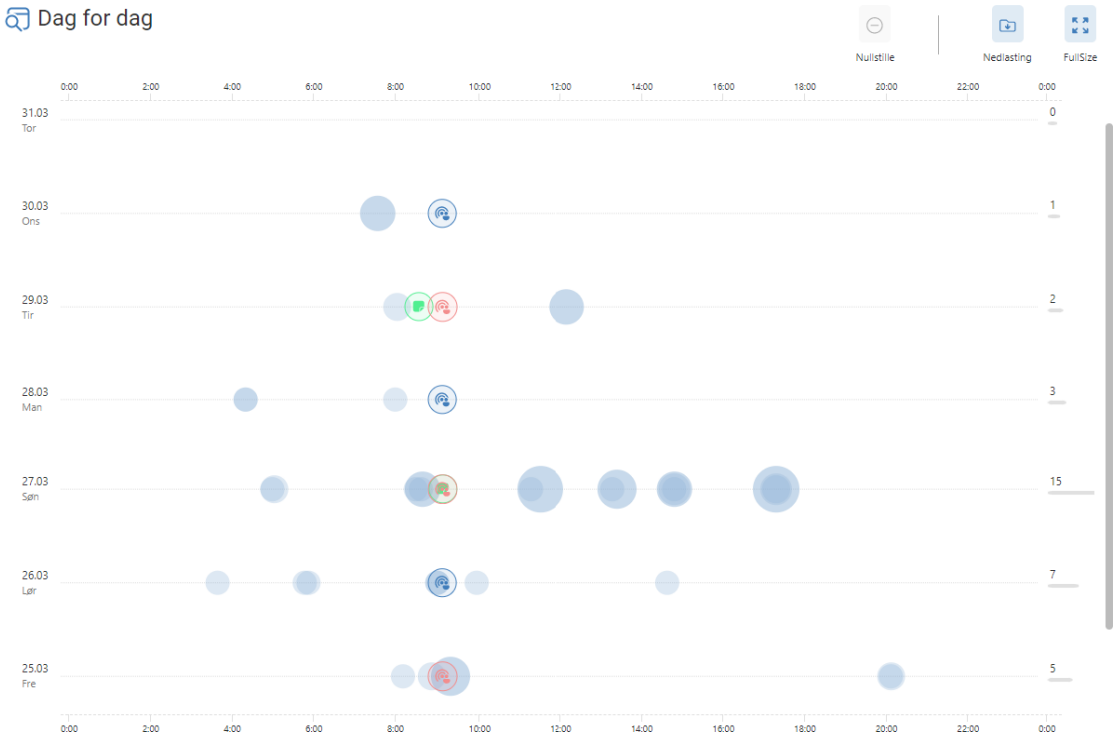
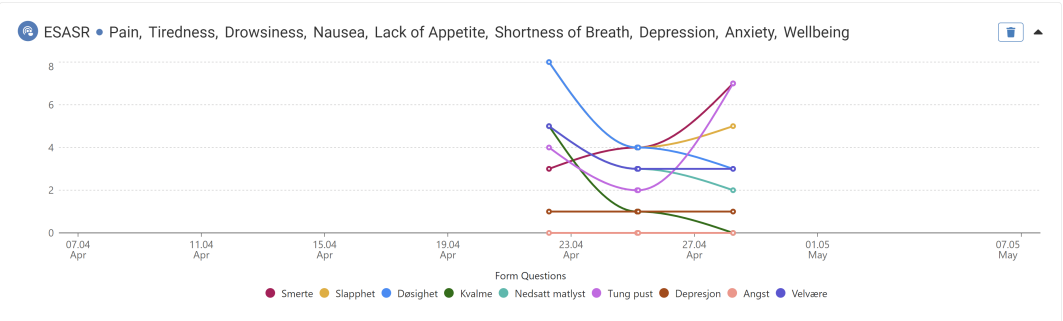


Figure 3.5: ESAS-r line graph from a patient in the clinical trial.



Chapter 4

Methodology and Methods

Research extends beyond just methods and techniques, and by understanding how research is conceptualized, one will arguably gain deeper insight into the implications of the chosen methods and broader understanding of the research findings (*Williamson and Johanson*, 2017, 4). This thesis draws on empirical *Mixed Methods Research* (MMR) utilizing quantitative and qualitative research methods. The following chapter presents an introduction to MMR, an outline of the pilot study and the clinical trial, and descriptions of the research methods.

4.1 Mixed methods research

Irregardless of some disagreements within the research community, Mixed Methods Research is generally characterized by the use of both quantitative and qualitative methods (*Tashakkori and Creswell*, 2007; *Williamson and Johanson*, 2017, 19). The Journal of Mixed Methods Research offers a wide definition stating that MMR is:

> research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry (*Tashakkori and Creswell*, 2007).

This is an inclusive definition, reflecting the broad usage of the term to describe perspectives that view it as a research method for data collection and analysis, a methodology integrating quantitative and qualitative approaches, a philosophy of research, or a set of procedures to use with existing research designs (*Williamson and Johanson*, 2017, 526). *Johnson et al.* (2007) have examined definitions of MMR from criteria leaders within the field. They identified five recurring themes of what is mixed, when or where it is mixed, the breadth of MMR, why mixing is carried out, and the orientation of MMR. The analysis led to an attempt to offer a more comprehensive description stating that MMR:

> is an intellectual and practical synthesis based on qualitative and quantitative research; it is the third methodological or research paradigm (along with qualitative and quantitative research). It recognizes the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative,

> complete, balanced, and useful research results ... Furthermore, the MMR paradigm offers an important approach for generating important research questions and providing warranted answers to those questions...

Their description goes on and states, among other things, that MMR partners with the philosophy of pragmatism and relies on qualitative and quantitative viewpoints, data collection, analysis, and inference techniques combined according to the logic of MMR. In contrast to the more general definition by Journal of Mixed Methods Research. *Johnson et al.* (2007) notably refers to MMR as a paradigm. While this is a view shared by many researchers, the philosophical foundations are yet up for debate.

4.1.1 Quantitative and qualitative research

A divide is commonly drawn between quantitative and qualitative research. Quantitative research encompasses empirical approaches that aim to collect, analyze, and display data in a numerical form, with the goal of generalizability through statistical methods (*Given*, 2008, 713). It seeks to describe trends and identify relationships between variables by testing theories about reality (*Migiro and Magangi*, 2011). On the other hand, quantitative researchers view the world as consisting of observable and measurable events and facts. They focus on complex and dynamic social constructs, and the assumption that the meaning of events, occurrences, and interactions must be seen through the eyes of participants(*Gorman and Clayton*, 2005, 3). Qualitative research is appropriate when the aim is "to identify, analyze, and understand patterned behaviors and social processes" (*Given*, 2008, 706). Even though the two labels are separate in some aspects, the distinction can be misleading. For instance, quantification of surveys or questionnaires is often seen in qualitative research, and quantitative researchers may translate qualitative gradations of quality to numeric values (*Given*, 2008, 713).

MMR is often referred to as "the third wave", and unites the strengths of both approaches by letting them complement each other by mixing, combining, and linking data to gain a deeper and broader understanding of the research problem at hand (*Johnson et al.*, 2007; *Migiro and Magangi*, 2011). *Creswell* (2014, 2) states that MMR builds on the assumption that "when an investigator combines statistical trends (quantitative data) with stories and personal experiences (qualitative data), this collective strength provides a better understanding of the research problem than either form of data alone". Selecting and integrating the most appropriate techniques, from quantitative and qualitative research, to investigate a phenomenon is often termed *methodological eclecticism* (*Tashakkori and Teddlie*, 2010, 8).

Among the weaknesses of MMR is the emphasis on the researcher being able to understand multiple methods and approaches, as well as having to know how and when to apply them appropriately (*Migiro and Magangi*, 2011). MMR can also be time-consuming and labor-intensive. Disagreements within the field exist, for instance concerning the vocabulary and definition of concepts and terms, which is related to the paradigm-method issue (*Tashakkori and Teddlie*, 2010, 19).

4.1.2 The paradigmatic elephant

There are several ways in which one may conceptualize the foundations of research. It is not the intent of this thesis to unfold Pandora's box of research philosophies and methods, and the opinions and arguments that follow. Still, it is worth dedicating a section to describing the biggest challenge of MMR.

A *paradigm* or *world-view*, is a "set of underlying principles which provides a framework for understanding particular phenomena " (*Williamson and Johanson*, 2017, 582). Paradigms within information science research are for example positivism, post-positivism, interpretivism, and pragmatism (*Kankam*, 2019). Some researchers prefer to label their research through other conceptual approaches such as qualitative, quantitative, or MMR (*Williamson and Johanson*, 2017, 17). There is a lack of agreement within the research community on how the latter approaches fit each other and other paradigms. Should they be placed within one specific paradigm, multiple paradigms, or should they be considered paradigms of their own? To elaborate, *Leavy* (2020, 3) argues that qualitative research is a multiparadigmatic, diverse field of inquiry encompassing researchers of different world-views like postpositivism and interpretivism. *Denzin and Lincoln* (2018, 9) describes it as "a field of inquiry in its own right..." and a "complex, interconnected family of terms, concepts and assumptions sounding them...". In contrast, *Gorman and Clayton* (2005, 3) puts qualitative research within the interpretivist paradigm. While quantitative methods often align with positivist research, qualitative with interpretivist research, and mixed methods with pragmatism, this is not always the case (*Williamson and Johanson*, 2017, 18). It is this discrepancy, in the definition of terminologies, that fuels the old paradigm-method debate on what world-views can be combined with what methods.

MMR has evolved gradually, but the issue related to combining quantitative and qualitative techniques persists due to their argued differences in philosophical and methodological underpinnings (*Migiro and Magangi*, 2011). *Tashakkori and Teddlie* (2010, 6) acknowledges the crucial relationship between methodology and conceptual issues, but claims that they are separable on several dimensions. Despite many mixed methods researchers' choice of methodological eclecticism, there is still confusion surrounding terminology making MMR conceptually unclear (*Tashakkori and Teddlie*, 2010, 6). Some believe that MMR is becoming a paradigm in its own right, others have chosen an a-paradigmatic, single-pragmatic, or dual-paradigm approach (*McChesney and Aldridge*, 2019). MMR is often paired with pragmatism that emphasizes the "what" and "how", focusing on the research problem and the research questions, rather than set philosophies (*Kankam*, 2019). A middle ground of *paradigm pluralism*, "the belief that a variety of paradigms may serve as the underlying philosophy for the use of mixed methods", has been suggested, but this is also where much of the criticism of MMR resides (*Tashakkori and Teddlie*, 2010, 8).

Although specific research methods are often linked to certain paradigms, one should nonetheless emphasize the matching of research questions to appropriate design, and be mindful of the practical consequences and the interpretation of findings (*Kankam*, 2019; *Williamson and Johanson*, 2017, 21). The choice of methods should be made in conjunction with how the research questions are framed, and pragmatic considerations concerning the purpose of the study; what is feasible regarding participants, data, time, and practical skills as well as ethics (*Leavy*, 2020, 5). Additionally, re-

searchers must consider what value mixed methods can add to the research, as opposed to using only one approach.

4.1.3 Choice of a mixed methods research approach

As seen from Chapter 2, scales and tools for pain and symptom logging often aim to directly translate subjective pain experiences into objective measures. Even though this way of conceiving and communicating pain has been questioned, one must recognize the need for a common language with which patients and HCPs can assess and communicate experiences in a systematic way. The goal of this research has not been to identify one true objective measurement of pain, if that is conceivable, but to collect, explore and interpret the experiences of individuals using Grasp, and how it may support patients and nurses in assessing, logging, and describing pain and symptoms. Emphasis has therefore been placed on what research methods were best suited to investigate the research questions, and the studies' limitations in terms of time, resources, and ethics. A mix of quantitative and qualitative methods, questionnaires and interviews, was deemed suitable to help explore the broad research questions. In that sense, my approach to MMR is similar to that of *Creswell* (2014, 2) who views MMR as a method in which "data collection, analysis, and interpretation hold center stage".

4.2 Study outline and research methods

While *methodology*, the theory of methods, refers to the overall roadmap of the research, *research methods* are restricted to the tools or techniques with which researchers collect their data (*Given*, 2008, 516). The following section discusses ethical considerations and presents an outline of the studies. It then proceeds to describe the research methods.

4.2.1 Ethical considerations

Ethics are essential to ensure the safety of participants and the quality of the research. Ethical issues, especially when dealing with human subjects, refer to issues relating to avoiding exploitation and ensuring the safety of participants, confidentiality, disclosure of the nature of the study as well as considerations of how the participants are being portrayed (*Leavy*, 2020, 6). In clinical research, one must be especially attentive to potential legal or moral issues. For example, data and knowledge about participants' backgrounds and health, both physical and mental, are sensitive and ought to be treated carefully. Only necessary information that is relevant for the research should be collected, and the researcher must be mindful of her relationship with the participants, and how to deal with information that may be difficult to bear (*Given*, 2008, 624). One must additionally consider the risk and negative consequences that research on patients, medical interventions, and drugs might have, to prevent harm. In addition, experimental clinical studies must be registered by the responsible authorities and participants should sign a declaration of consent (*Röhrig et al.*, 2009). Although these procedures are important and considered the gold standard, adhering to legal requirements does not imply that the study was conducted in a way that ensured participants' interest (*Brown*

et al., 2016). Ethical review boards and committees may have understood the study application differently than the researcher's intention, and several ethical dilemmas are decided in the field when they arise as "research can change radically between design and implementation" (*Brown et al.*, 2016).

For the pilot study, no personal data were gathered. The participants were informed about the types of data collected: age, gender (optional), and squeeze data. Consent was given orally at the beginning of the interview. All data were anonymized by assigning each participant to a randomized letter from the Latin alphabet. Squeeze data was labeled with the corresponding letter and saved on my Grasp account. Participation was voluntary, and they could withdraw at any time without consequences. No compensation was given. For the clinical trial, several considerations had to be made, especially concerning the patients' well-being. Before the trial, an application was initially sent to The Regional Committees for Medical and Health Research Ethics. The final assessment was received in October 2021, stating that approval from the committees was not required to carry out the project. A new application was sent to the Norwegian Center for Research Data, and was approved by January 2022. Participation was voluntary and patients could withdraw at any time without consequences. No compensation was given. Data collected were encrypted and stored in a restricted cloud service. Exceptions are interview recordings that were stored on the recording device until they were transcribed and anonymized. Data collected from patients include answers to questionnaires, squeeze data and digital ESAS-r forms from those who used Grasp. Nurses' names and emails were collected when they created a user profile in the Grasp system to manage their patients' Grasps. In Phase 1. of the trial no written consent form was provided as ESAS-r is the stated procedure at the ward. Oral consent was given by those who answered the questionnaire. Patients in Phase 2, and participating nurses in both phases, received written information explaining the purpose of the study and the collection and storage of data. Nurses also talked to patients they deemed fit for the study and further clarified if they had any questions. Written consent was collected by those who wanted to partake, see figure 7.5 and 7.6 in Appendix B.

Palliative patients are an especially vulnerable population and they may experience considerable fluctuations in daily condition and functioning. *Brown et al.* (2016) discusses five provocations of ethics in HCI to foster conversation and reflection on accepted positions. The provocations highlight among other things issues concerning informed consent, the power-imbalance between the researcher and the research subjects, and whether participants benefit from the study. In practice, the recruitment of participants was done by the Heads of Section of the cancer ward, two nurses with extensive experience in the field. They recruited other nurses who then again provided insights on which patients may fit the requirements of the study. The researcher had no contact with the patients. This reduced the researcher burden, and arguably led to fewer disruptions in the everyday routine of nurses and patients. There are however some trade-offs. As an example, it is not known how different nurses conveyed information to the patients or asked them for consent in practice, nor the extent of the power imbalance that occurs between them. For Phase 2. nurses carefully selected potential patients to use Grasp. All patients asked to partake agreed, but this does not disregard the fact that some may have felt obligated to do so. In this type of study, questions regarding the participants' agency and how the study may affect them must be attended to. There is also the question of who benefits from the study and what the patients

themselves gain from it. This is further discussed in Chapter 6.

4.2.2 Pilot Study

Pilot studies are usually small trial runs of the main study, aiming to test methods, instructions, and equipment to identify and correct potential problems (*Sharp et al.*, 2019, 265). This is important in the early stages of research before embarking on the main study. Pilot studies generally last for a shorter amount of time, compared to the main study, and involve a small number of participants (*Given*, 2008, 624).

To test the overall study design I invited my roommate, F 25, to partake in a practice session, going through the tests and the interview questions. Possible changes and improvements were discussed. The feedback mostly revolved around the importance of precise language during the think-aloud. We also agreed that participants should be allowed to perform the warm-up squeeze test twice, if necessary. This would give them a second chance to adjust their squeezes if their first time was far off.

Overview

From existing work on tangible pain logging, squeeze pressure has gained the most attention (*Adams et al.*, 2018; *Schaffner et al.*, 2012). This study has instead used squeeze duration as a measure of intensity. The pilot study was not a replica of the clinical trial, but it reviewed relevant conceptual aspects of Grasp. It took a step back from pain and symptoms, shifting the attention to the general idea of tangible interaction and non-verbal logging of experiences through squeezes. It also aimed to explore users initial thoughts and impressions of Grasp, and the relationship between visualisations and the physical interaction.

Between January 19th-28th 2022, eight students were invited to individual 1-hour sessions where they interacted with the Grasp hardware and software. The pilot study took place at the campus of the University of Bergen. At the beginning of the interview, the participants received a Grasp to hold, squeeze, and feel. They were then presented with the web interface, but without any data. Participants were encouraged to navigate the site freely, share their thoughts, or ask questions. To familiarize themselves with how Grasp maps squeeze duration to scores and visualizations, the participant produced a single data point by squeezing Grasp as demonstrated in Figure 4.1. Data was then uploaded, by the researcher, to the interface. The participant proceeded to perform a set of Think-aloud tasks on the interface, before carrying out a set of randomized squeeze tasks. A complete protocol is included in Appendix A.

4.2.3 Clinical trial

Clinical research, which can be rooted in both social and medical science, is research related to experiences and descriptions of individual and interpersonal problems, and transition and change, where the latter two can occur as part of ones life course or medical intervention (*Given*, 2008, 79). It encompasses studies on human behavior, interaction, cognition, and somatic experiences from a variety of perspectives, and is generally categorized into experimental (interventional) or observational (noninterventional) research, depending on whether the researcher assigns the exposure or not. Clinical

Figure 4.1: Demonstration on how to squeeze Grasp version 2.0 in order to ensure that the interaction is logged. This issue was fixed in Grasp Pilot Edition.

experimental studies aim to compare treatment procedures within a patient population, and demonstrate the clinical or pharmacological effect of drugs, procedures, vaccines, or medical devices (*Röhrig et al.*, 2009).

Overview

The clinical trial at a cancer ward was a two-phased, experimental and non-randomized controlled trial carried out between February 28th and May 3rd, 2022. The goal was to study whether Grasp, compared to ESAS-r alone, could support palliative cancer patients in logging, assessing, and communicating their pain and symptoms. Additionally, the trial studied how Grasp may support nurses in caring for and treating patients, especially in understanding their symptoms. By conversing with nurses in the early phases of the project, it was revealed that despite ESAS-r being the recommended form at the ward, it was rarely utilized in practice. Phase 1. was consequently conducted to form a baseline. While it would be ideal to test ESAS-r and Grasp separately, we were in no position to make alterations in stated clinical practice, and Grasp was not applied as a stand-alone tool.

Phase 1, lasted from February 28th till March 30th, and included 26 patients and all nurses and health care workers at the ward. In this phase ESAS-r was administered, verbally or on paper, to patients once a day, ideally from the day of hospitalization until discharge. Before leaving the hospital, the patients received a paper questionnaire on their experience of ESAS-r. Phase 2. lasted from March 14th till May 3rd, and involved eight patients and six nurses. Here, Grasp was used in addition to daily ESAS-r. During the trial, the accuracy (i.e., trying to squeeze according to target duration), and the details of the Grasp software, were not the focus of attention in considerations of the patient group. Patients were not presented with the technical details of the software, and they were simply asked to squeeze Grasp harder and longer when experiencing more pain. With advanced cancer patients it is recommended to prioritize symptoms according to their severity *Shoemaker et al.* (2011). The patients' most severe symptom were identified through an initial screening with ESAS-r. Grasp was then used to log the occurrence and fluctuations of this symptom, and the tool could be used as much as the patients wanted/needed. Nurses synchronized the Grasp data with their iPad each morning. Before leaving the hospital the patients answered questionnaires on their

experience using Grasp.

Nurses, especially the Heads of Section, were involved early in the project to test out Grasp, and to provide feedback on critical issues concerning software, visualizations, and functionality. They received online and face-to-face training on how to use Grasp, which they later passed on to other nurses interested in the study. Nurses' insights were valuable, and the software development team provided necessary changes before the trial began. In both phases, nurses were responsible for administering and explaining to the patient how to use ESAS-r and Grasp. Nurses also distributed questionnaires after each phase. After both phases were completed, participating nurses received a questionnaire on their overall experiences of Grasp compared to ESAS-r alone. To supplement this data, nurses were also invited to individual, semi-structured interviews on May 3rd, 2022. The interviews took place at the hospital and lasted between 30-50 minutes. See Appendix B for further details about the materials. The following Tabel 4.1 lists the equipment used in both studies.

Table 4.1: Equipment for the pilot and clinical trial.

Equipment	Comment	Pilot	Clinical Trial
1. Grasp		Version 2.0	Version Pilot
2. iPhone	To upload data to the software.	O	
3. Laptop	A laptop to view the web interface. Thinkpad T14, with a touchpad and charger.	O	
4. Notebook		O	O
5. List of squeeze prompts	A list of randomly assigned squeeze instructions to be used in the individual squeeze tests.	O	
7. Interview guide		O	O
9. Recorder	ZOOM H1n Handy Recorder, version 1.19		O

4.2.4 Sampling

Both studies employed non-probability sampling, i.e. choosing participants based on who is available or who fits the purpose of the study, a common technique in quantitative research. It allows the researcher to construct their own sample which is suitable when studying a particular group in some depth or for pilot studies (*Given*, 2008, 563). It does not permit estimation of sampling error as there is no random selection involved, and it may therefore be subject to a sampling bias.

In the pilot study, participants were invited through *convenience sampling* by selecting all eligible participants that could be found. With convenience sampling, the researcher selects participants until they believe they have sufficient data (*Williamson and Johanson*, 2017, 373). Data was reviewed continuously after each session, and recruitment ended after eight participants. In total, four female and four male students partook. The mean and mode age was 25 years old with a range of 2. All are currently enrolled in graduate or undergraduate studies, except one who is a former student.

For the clinical trial, *purposive sampling* was appropriate to ensure that the sample was befitted to the purpose of the study, following a set of criteria. It is suitable when the emphasis is on an in-depth understanding of a specific case (*Williamson and Johanson*, 2017, 374). The population encompassed patients and nurses at a cancer ward. No specific criteria were set for nurses in Phase 1. Nurses' criteria for Phase 2. include (1) working with patients at the ward during both phases and (2) being willing to participate. The patients' criteria for both phases were (1) admitted to the cancer ward, (2) Norwegian speaking, (3) were willing and able (with or without assistance) to understand and complete the forms, (4) in the case of Grasp, were able to understand the concept and to give written consent. Patients' eligibility was determined based on their overall condition as judged by nurses. Twenty-six patients, mostly palliative but some also suffering from hematological diseases completed Phase 1. Patients who were only admitted to the ward for one day, left the hospital without answering the final questionnaire, or were unable to complete the study due to deteriorating health or death, are excluded. Nurses could not confirm the exact number of patients this amounted to. In Phase 2. (Grasp and ESAS-r) ten palliative patients were initially invited to partake, all of whom agreed. Two patients were excluded due to deteriorating health. A total of eight patients completed this phase. After the completion of both phases four nurses agreed to partake in interviews.

4.2.5 Semi-structured interviews

Semi-structured interviews make use of pre-prepared questions and prompts, administered flexibly to capture a wider picture of the participants perspectives. Interviews have the advantages of direct contact between the interviewer and the interviewee, making it possible to ask complex questions, follow-ups, and gain additional information (*Williamson and Johanson*, 2017, 389). The interviewer can clarify and correct misunderstandings, and the setting permits some level of control. Interviews also have their disadvantages: they are time-consuming, and the quality of an interview depends greatly on the interviewers experience and how she is perceived by the interviewee. Individual semi-structured interviews were performed in both studies, accompanied by separate interview guides included in the Appendixes. The guides are quite exhaustive to ensure that all topics were covered, but questions were administered flexibly. In the pilot study, the interview took place after participants had performed all tests. Participants were nevertheless encouraged to share their thoughts during the entire session. Nurses' interviews were recorded and then transcribed verbatim.

4.2.6 Questionnaires

Questionnaires, which can consist of closed or open-ended questions, are a well-established technique for collecting large amounts of demographic data and users opinions (*Sharp et al.*, 2019, 278). They are flexible as they can be administered orally or in text, and on paper or digitally. Questionnaires are often performed in conjunction with other techniques. In particular, a quantitatively oriented questionnaire can be useful to generate a general understanding of a set of questions and to identify interview questions for elaborate qualitative investigation (*Given*, 2008, 846).

Three Norwegian questionnaires were made for the clinical trial, refer to Appendix B.) for the original questionnaires. Two of them were directed towards patients, one for each phase. Both versions contain the same six questions about participants' experience of the tool they used. These were answered on a 5-point Likert scale from 1 (*a very small degree*) to 5 (*a very large degree*). There was also the option of *not relevant*. The Grasp questionnaire further included four statements about Grasp, answered on a scale from 1 (*completely disagree*) to 5 (*completely agree*), and three open-ended questions. Patients who were able to fill out the forms themselves could do so, while some required nurses' assistance. The last questionnaire was handed out to nurses after the completion of both phases. It inquired about their opinions using Grasp and ESAS-r, as opposed to ESAS-r alone, through four Likert-scale questions (*a very small degree - a very large degree*, seven Likert-scale statements (*completely disagree - completely agree*), and two open-ended questions.

4.2.7 Think-aloud

During a think-aloud participants explain out loud what they are thinking and doing, to reveal their thought processes, their planning, and their initial impressions, while carrying out specific tasks (*Sharp et al.*, 2019, 524). Think-aloud is often applied in usability testing (*Nielsen*, 2012). This was not the goal of the pilot. The intention was to let participants interact with the system as a whole, and to investigate their experiences of tying together physical interactions and visualizations. It is nonetheless crucial that systems intended for health care are easy to use. This was estimated by looking at the participants' overall performance, in terms of the number of correct tasks and by asking them directly in the interview. The think-aloud also revealed several issues with the interface and a summary of those is included in Chapter 5.

The Think-aloud consisted of ten Norwegian tasks on an existing dataset on the Grasp Interface. It was performed using a laptop and touch-pad. The tasks were designed to simulate what users typically might want to accomplish on the interface, and they all have predefined answers. However, some could be solved in multiple ways. Tasks were presented orally one by one, and notes of which tasks participants had difficulties with were taken. To gain insight into their overall performance a maximum score of 10 points was calculated: 1 point for each task completed, and 1/2 point if they had to ask for help. If the wrong answer was provided or they gave up, 0 points were given. Participants could still receive points if they navigated the website correctly, but a technical error occurred right before the answer was revealed. Tasks include "when (what date) was the first squeeze registered?", or "can you find November 16. 2021? How many observations were made on this day?". All tasks are listed in the Appendix.

4.2.8 Randomized squeeze test

To prepare for the second test participants performed a warm-up test by squeezing Grasp once for 1s, 2s, 3s and 4s. Visualizations were examined, and the warm-up continued by them squeezing Grasp three times for 1s, then for 2-3s, and for $\geq$4s. This is consistent with how squeezes are categorized and labeled by the software. Each participant was responsible for keeping track of the time. They were also instructed to

take breaks between squeezes, ensuring that each squeeze was recorded individually. Data were again uploaded and reviewed. Upon request, this stage was repeated once.

For the main test, a list of twelve Norwegian squeeze prompts was read out loud to each participant. One by one, with breaks in between. The lists contained three types of prompts, four of each type: *kort* (1s), *medium* (2-3s) or *lang* (≥4s). An online randomization tool was used to ensure that each participants' arrangement was unique. Table 4.2 is identical to the table seen in the Chapter 3, with an additional column of squeeze prompts. As the duration of the prompts is quite short there is little leeway. Participants received 1 point for each correctly categorized squeeze, hence a maximum of 12 points. Whilst it would be beneficial to use more prompts and gather a larger set of data, the intention was to keep the participant burden low.

Table 4.2: Overview of the automatic score, category, and prompts used during the squeeze test and how they relate to squeeze duration.

Duration in seconds	Automatic score	Automatic category	Test prompts
0	0	N/A	N/A
1	2	Low	Kort/short
2	5	Medium	Medium
3	7	Medium	Medium
4	9	Hard	Lang/long
>4	10	Hard	Lang/long

4.2.9 Data analysis

Quantitative data

The quantitative data were cleaned and then analyzed through Microsoft Excel using descriptive statistics. Descriptive statistics are methods to summarize or describe the observations and their distribution (*Rowntree*, 2000, 19). As the questionnaires gathered *ordinal data*, i.e. data that can be ranked or categorized, the median and mode are suitable measures (*Rowntree*, 2000, 30). With this type of data, there are no established intervals between measurement scores on the scale. For example, *agree* is arguably more positive than *disagree* but there is no way of telling just how big the difference is (*Williamson and Johanson*, 2017, 435). For the sake of analysis, Likert-scale questions are often transformed into numeric values with the assumption that they can be treated as *interval data*; data with equal intervals. While questionnaire statements have been mapped to a 1-5 scale, they will not be treated as interval data to 1) preserve the nuances of ordinal data and 2) due to the small number of respondents.

Inferential statistics encompass using the observations from the descriptive statistics to make estimates or predictions (*Rowntree*, 2000, 19). Due to the ordinal nature of the data, a non-parametric test was appropriate to compare the two conditions, ESAS-r and Grasp. As the sample size of the questionnaires was small, this will decrease statistical power. A two-tailed *Mann-Whitney U Test* (MWU) was performed using IBM SPSS v.27. MWU is a non-parametric test often described as a test to determine

whether there are any differences in the median values of two distributions (*Williamson and Johanson*, 2017, 447). It can more accurately be described as a test comparing the sum of ranks of the dependent variable for the two groups. The MWU can be applied to small samples, and does not assume a normal distribution of data (*Nachar*, 2008). However, the independent variable must be nominal with two levels, and the dependent variable(s) ordinal or continuous. The null hypothesis, H_0 states that there is no difference between patient responses to ESAS-r and patient responses to Grasp (similar distributions), and H_1 states that there is a difference between patient responses to ESAS-r and patient responses to Grasp (dissimilar distributions). The two conditions are not mutually exclusive as ESAS-r was present in both. This can have affected respondents in the second using Grasp.

Qualitative data

Qualitative data from the studies were analyzed separately through thematic analysis, in which the data are segmented, categorized, summarized, and reconstructed to capture the essence and most important concepts within the dataset (*Given*, 2008, 857). *Braun and Clarke* (2006) describes thematic analysis as a recursive process of constantly going back and forth between the data, the coded extracts, and the themes, reviewing choices, and making changes as needed. It is an accessible and flexible approach to analyzing qualitative data, and it gives the researcher freedom to determine themes and prevalence of those in multiple ways (*Braun and Clarke*, 2006). This thesis uses a theoretical approach to thematic analysis, following the guidelines by *Braun and Clarke* (2006). In a theoretical approach, one may code with a specific research question in mind, and the analysis is driven by the theoretical and analytic interest of the researcher.

Chapter 5

Pilot Study Data and Results

This chapter covers the data and results from the pilot study, by first presenting the outcomes of the tests, followed by a thematic analysis of the interview data. Here, three main themes were identified: design that invites interaction and facilitates ideas, squeezing as an input method, and visualizations that support tangible interaction. Participants identified several issues with the software and hardware, and offered suggestions on improvements. A section is therefore dedicated to their feedback, before discussion how the findings relate to the original research questions. At last limitations and considerations are presented.

5.1 Test data and results

Participants are referred to by their randomly assigned letters, in no particular order: PI, PB, PS, PK, PX, PQ, PT, and PF. When asked about how well they master technology and whether they are comfortable using and adapting to new technologies, all the male participants rated themselves to be fairly good or excellent. PT said, "I often use new technologies at work ... I would say I am a ten out of ten or nine out of ten". Three female participants expressed their abilities as moderate, and one rated them as poor. PB said that it "depends on how personally invested I am. I easily get tired of it if I encounter problems". Despite these differences in self-perceived abilities all students performed well.

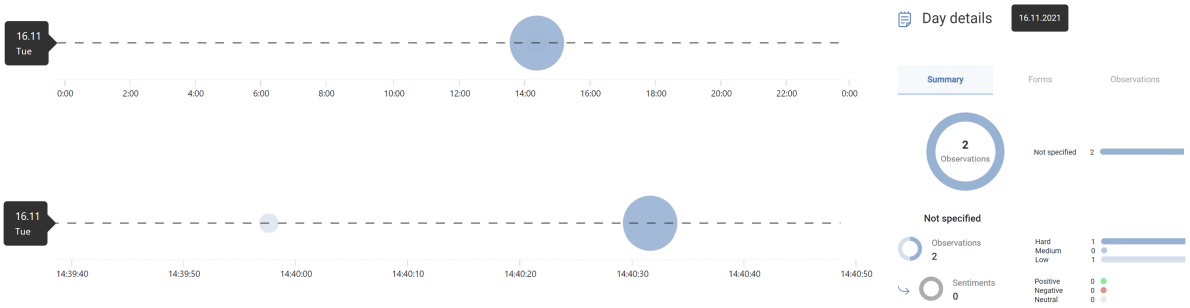
5.1.1 Think-aloud results

Participants were able to complete most of the tasks, regardless of some difficulties related to the design of the interface. PB and PI completed all tasks, receiving a full score. The mean score was 9 out of 10 points with a range of 2. All participants completed tasks 2, 4, 6, 8, and 9 without help, but with varying amounts of navigating. Participants generally found the tasks manageable saying that it went "well" or "it was fine", and that it became progressively easier as they became familiar with the interface. PX stated, "I feel like I know it now after having tried it ... Would have been easier if I read everything properly". PT described the tasks by saying, "most of them went well, but some were not that intuitive...", and PK commented that, "as soon as I figured things out it made more sense. Made sense when I got to click around and get used to

it. Now I feel like I am in control".

The focus has not been to identify specific usability issues. Nonetheless, it became clear from observing the participants that work is needed to improve the overall experience. The lack of intuitiveness and familiarity with the interface led several participants to choose more cumbersome actions than required to solve the tasks. To elaborate, Task 1. was the one that most struggled with. Here participants are asked to find the date of the first registered squeeze. The answer is written at the very top of the front page, yet it was overlooked by all but two. Two other participants solved the task alternatively by looking at the visualizations. A couple of participants explained that they did not pay attention to the date because they thought it was a hyperlink. Two participants also attempted to find the date by retrieving all data from the past three years, by clicking and scrolling back in time, eventually giving up. A similar issue was seen with Task 5. where the goal was to report the number of squeezes on November 16th, 2021. Two participants answered that there was only one observation that day. This is incorrect, as there are in fact two as can be seen under "day details". This is illustrated in Figure 5.1, where one can see two horizontal timelines. The top one is an overview of the day in its entirety, and the bottom one is a zoomed-in screenshot of the same timeline.

Figure 5.1: Screenshot of the web interface showing squeeze data from November 16th, 2021. To solve Task 5 participants had to select or enter the correct date in the date-picker (not in picture), and then read the information in "day details", or zoom in on the single circle to reveal the circle underneath.

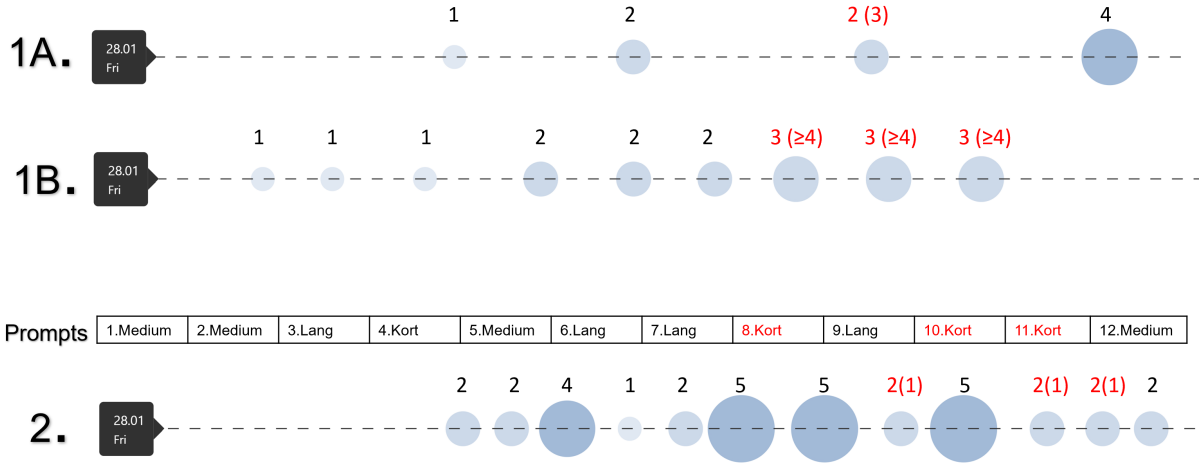


5.1.2 Squeeze test results

The squeeze test had a maximum of 12 points, one for each prompt. The mean score was 10 points, with a range of 4. PF and PB, received a full score by replicating all squeezes correctly. PB also got a full score on the think-aloud. All but two participants thought the squeeze test went "well", "easy" or described it as "not too difficult". PS described it as, "stressful to use time. It is difficult to count if I am doing something else as well" and PI said, "too difficult to count on my own". All participants mentioned that the data visualizations, circles of varying sizes, made sense. They reportedly aligned with the participants physical experiences. Figure 5.2 is a screen-capture of the data visualizations from PQ's squeeze test, including the randomized prompts.

Results from the test are summarized in Tabel 5.1, and an overview of each participant is included in Tabel 5.2. By looking at the scores alone, it appears that participants struggled with the *kort* prompt the most. Out of the registered squeezes 70 % of the *kort* prompts were correctly produced compared to over 90 % for both *medium* and

Figure 5.2: Squeeze test data from PQ. 1A. and 1B. display visualizations from the warm-up tests, and in 2. the results from the randomized test can be seen. The red numbers and text are cases in which PQ was unable to produce the correct squeezes. The numbers in parentheses show target squeeze duration.



lang. Five participants made at least one error when trying to replicate a *kort* squeeze, most often squeezing for 2s. One second off from the target value is not a large deviation, but it becomes apparent when the margins are small. In two individual instances, where a participant received a *kort* prompt, data is missing. The participants may not have squeezed Grasp hard enough or long enough. One must keep in mind that the compression of a squeezable object has a duration in itself. When encountering the *medium* prompt only two failed to meet the criteria. PX squeezed Grasp too short, PT too long. All participants except one produced all *lang* squeezes correctly. PX missed her *lang* prompts by 1s.

While PX produced all twelve squeezes, four of them were too short, and she seemed to be counting too fast. PI had the opposite problem in which her counting was too slow. For example, she only produced one correct *kort* squeeze. The differences in scores from the squeeze test were further highlighted during the interview. A recurring comment was that the duration of different squeezes should be longer to make them more distinguishable. As PX explained, "it was not so hard to use seconds but the distance between the levels is too small... 2 and 4s feel very similar...". However, participants were varied in their opinions on what prompts were the most challenging to reproduce. PK found *lang* squeezes easy to replicate but had a difficult time with *kort*. PI also had problems with the *kort* prompt saying, "kort was harder than I thought. 1s is surprisingly short. 2-3 seconds is the easiest...". Although both PF and PB received a full score, they both described the *medium* prompt as challenging. They characterized the other prompts as easy. PF said, "the hardest was 2-3s but all the others were very easy". No participant expressed difficulties with the *lang* prompt, but PF commented that his hand was getting tired by longer prompts because he did not know how hard he was supposed to squeeze.

Some attention should be given to the differences in squeeze prompts restricted by the software, which seems to be reflected in the participants' performance. There is a substantial difference between the prompts and how hard they presumably are to

produce. The *kort* prompt is only supposed to be 1s long. The *medium* prompt, on the other hand, must be between 2-3s, providing some leeway. While the *lang* prompt has no upper limit in terms of seconds. An off-set score has not been calculated, as it is evident from the table that the offset is $\pm$1s for all the wrongly produced prompts.

Table 5.1: The table contains a summary of all squeeze test results. The last row shows how many participants made at least one mistake with this prompt.

Prompt	Total prompts	Total prompts registered	Correctly registered	Correctly registered %	Participants involved
Kort	32	30	21	70 (out of 21)	5
Medium	32	32	30	96.7	2
Lang	32	32	29	93.5	1

Table 5.2: The table shows the randomized prompts each participant received, their results in seconds, and their total score. Missing values (N/A) or wrongly produced squeezes are colored red.

	PK		PQ		PX		PT		PF		PB		PS		PI	
1	Lang	5	Medium	2	Kort	1	Kort	1	Kort	1	Medium	2	Medium	2	Lang	5
2	Kort	2	Lang	4	Lang	3	Kort	1	Medium	2	Lang	5	Medium	2	Lang	6
3	Lang	5	Kort	1	Lang	3	Kort	1	Medium	3	Lang	6	Lang	4	Kort	2
4	Medium	2	Kort	1	Lang	4	Lang	5	Lang	5	Medium	2	Kort	1	Medium	2
5	Medium	2	Lang	4	Kort	1	Lang	5	Kort	1	Medium	3	Medium	2	Medium	3
6	Kort	1	Kort	2	Medium	1	Lang	5	Lang	5	Lang	6	Lang	5	Kort	2
7	Lang	4	Medium	2	Medium	2	Medium	2	Medium	3	Kort	1	Lang	5	Medium	3
8	Lang	6	Lang	4	Lang	3	Lang	5	Medium	3	Kort	1	Kort	2	Medium	3
9	Kort	N/A	Medium	3	Medium	2	Medium	2	Kort	1	Kort	1	Lang	5	Lang	6
10	Medium	3	Medium	3	Medium	2	Medium	4	Lang	5	Kort	1	Kort	2	Kort	1
11	Kort	1	Lang	5	Kort	1	Medium	2	Kort	1	Lang	6	Kort	2	Kort	2
12	Medium	3	Kort	N/A	Kort	1	Kort	2	Lang	5	Medium	2	Medium	2	Lang	6
Total	10/12 (11)		10/12 (11)		8/12		10/12		12/12		12/12		9/12		9/12	

5.2 Thematic analysis

Three themes of interest with underlying sub-themes were identified. The first is "design that invites interaction and facilitates ideas" encompassing participants' impressions of the hardware and imagined use cases. The second is "squeezing as an input method" describing participants' views on squeezing to log experiences, and at last "visualizations to support tangible interactions" that consider participants' perspectives on the relationship between squeezes and visualizations.

5.2.1 Design that invites interaction and facilitates ideas: "squeeze it like a distraction, like a fidget spinner"

Participants were curious and eager to interact with Grasp and they shared diverse ideas of what the hardware reminded them of. The combination of physical properties including size, color, and shape, evoked associations with other already existing objects. Most often mentioned was a bean, then a stress ball, and a sex toy, the latter attributed to its bright color and silicone material, and a fidget tool. Three participants shared that they were pleasantly surprised by how soft it was, expecting it to feel as firm as hardware normally does. PK said, "I was surprised because it does not look that squeezable but it felt nice to squeeze", and PT said, "it is softer than I expected ... thought it would feel more comfortable". PI expressed, "I am skeptical of mixing soft materials with technology". She also did not like that the silicone felt a bit "sticky". PB said "handy size. Squeezable". Participants were mixed in their opinions and preferences on its size and material. Those that compared it to a stress ball also wanted it to be more "stress-ball-like". Nevertheless, the majority enjoyed squeezing Grasp, describing it as "soft"," comfortable", "squeezable", and "natural". One said it felt like holding a hamster, which was an interesting observation.

Grasp was introduced to participants as an experience logging tool where the intensity of the experience is represented by squeeze duration. Associations with other objects were again brought up when discussing what Grasp could be used for. Several suggestions materialized, including using it for personal improvement or as a fidget toy. Participants' answers reflected both what they personally would utilize Grasp for, like managing their diet, and how they imagined others might use it. For instance, one participant who recently became a father saw the potential of using Grasp to track morning sickness. Another user thought it would be handy for people suffering from mental illnesses during depressive episodes, or for pain. Using Grasp to express anger or stress was frequently proposed. PX believed using it as a physical outlet could help relieve these experiences. Half of the participants also thought that Grasp could be a great tool for distraction. PK expressed that one could "squeeze it like a distraction, like a fidget spinner". Three participants specifically said that it might help stop cravings, keep track of diets and bad habits. It would enable easy logging, and potentially help divert ones' focus from the experience. PX proposed that "you can squeeze it every time you really want chips but manage to not actually eat it". Similarly, PB said, "if you want to stop thinking about something like eating candy or smoking. You can squeeze Grasp and then see trends of when you have cravings". PI had a similar remark and explained "you can fidget with it to forget and think about something else". Several other ideas were also shared. PT thought Grasp could be used to log everything that happens periodically, and PQ explained that it could potentially help children express their feelings to their parents.

Tangible artifacts often draw inspiration from everyday objects. Familiarity can promote engagement, while more ambiguous representations may be linked to curiosity, exploration and reflection (*Price et al.*, 2013). In that sense, Grasp falls somewhere between. While it is reminiscent of a ball or stone, the overall form factor allowed the participants to imagine multiple use cases. Most notable were the examples of using Grasp as a tool for distraction or relief of experiences like anger and stress. It seems

like the design, that draws on the ideas of affective and tangible interaction, indeed embodies some of these aspects (*Guribye et al.*, 2016).

5.2.2 Squeezing as an input method: "the squeezing was logical. It makes sense"

Altogether, participants were positive about physically engaging with Grasp, and using squeezing duration to log experiences of increasing intensity. When asked whether it was easy or difficult to perform the squeeze tasks, the majority described it as "simple" or "it went well". PB said, "it was not too difficult. Only need a little training before you get the gist. The concept is fine...", and PF said, "the squeezing was logical. It makes sense and it will probably become easier with more practice...". PX thought that "the concept is nice but difficult to hit the small margins... if you have more time between the prompts, you can think less". This is consistent with the results from the squeeze test. All participants wished that the duration of intervals were longer to make them more distinguishable. Several were surprised at how short 1s is. Two participants had a hard time using duration describing it as "stressful" and "difficult". PX thought it went fine but added that "I do not do this often. I rarely have to measure things in 1,2 or 3 seconds so it was not that easy".

PX imagined that squeezing would be practical in situations where writing something down was inconvenient, and PT said it would be convenient when tracking "how many times you do something... it is easier than Excel". While PK acknowledged that logging through physical interaction was handy, he personally would prefer just using pen and paper. PI, who is a regular journal writer, said it would be better to just write a log. Both suggested that Grasp could be used as a distraction, but neither commented whether writing down the experience would have the same effect.

When asked if they would have preferred to interact with Grasp differently, squeeze pressure was mentioned by all especially for use cases like anger. Squeeze pressure requires the same grasping action as squeeze duration, and the suggestion may again be influenced by Grasp's shape/material, or associations to other objects. However, only one participant could for sure say that he thought squeeze pressure would be better than duration. PS was satisfied with squeeze duration as an input method, except for the lack of feedback when squeezing. PT even said, "it was nice to spend some energy on counting...". Others argued that different contexts might require different methods. PQ stated that "pressure might be nice if you are going to use it for anger, but if you want to use it for stress it is better to look at the frequency of the squeezes, like patterns". A couple of participants also brought up drawbacks of using squeeze pressure, saying that it would be difficult to reproduce squeeze pressures consistently and that pressure seemed "abstract" or "imprecise". This was also seen in the feedback on Keppi where some users described squeeze pressure as "too subjective" (*Adams et al.*, 2018). PS stated that pressure would be problematic if "one has arthritis or is in a bad condition" and PX said, "what if I work out or my arm is tired?". Five participants mentioned that the number of squeezes recorded or squeeze patterns, could be an easy way to log experiences. PX suggested, "one squeeze could be something small or of less importance while if you squeeze many times, like pumping, it could illustrate something stronger. A physical outlet". PI who did not enjoy using squeeze duration said,

"the number of squeezes would have been the easiest, I do not think pressure would be nice...".

5.2.3 Visualizations to support tangible interactions: "it helps to see my mistakes"

Despite the identified shortcomings of the interface, it was revealed that participants experience of squeezing were well in line with the actual visualizations of squeeze data. All eight participants expressed that it made sense that the size of the circles depended on the duration of the squeeze, and they were delighted to see the data corresponding to their tangible experiences. PQ declared "it was easy. It went well and it looked as I thought it would...". PT said, "the data match my sensory experience. I can see that the size of the circle is consistent with the duration of my squeezes" and PK explained that it "went well. Makes sense that time decides the size of the circle". Similarly, PS commented, "it makes sense compared to what I did". Participants did not provide much feedback on the relationship between automatic scores and categories, except for PK who described it as "a little confusing".

Participants appreciated the automatic generation of visualizations, and they enjoyed seeing the relationship between circle size and squeeze duration which they deemed intuitive. Yet, they conveyed dissatisfaction with how the interface presents the data, especially how circles close in time sometimes would overlap completely. PT said, "it works quite well with the circles, but I do not like it when they overlap". Likewise, PI said, "it is hard to see when circles overlap". Participants particularly enjoyed the "day by day" and "day details" overviews, and thought it was useful that one could see past interactions and summaries of those. The visualizations also provided the participants with feedback on their squeezes. Seeing the visualizations during warm-up helped them readjust themselves and become more aware of how they count seconds. PB said, "it is nice to see the visualizations of my squeezes. It helps to see my mistakes" and PX agreed by expressing "when you realize you count in a certain way, after seeing the data, it becomes easier." She also said, "I can see that I count a little too fast". Similarly PI realized "I count slower than I thought".

Affective interaction takes a non-reductionist approach to interaction, and visualizations should not be as strict as to enforce categories and representations (*Höök*, n.d.; *Krøger et al.*, 2015). The somewhat ambiguous (circles) representation of data seemed not to hinder participants' ideas of what the tool could be used for, nor restrict how one inputs data. Although they were told that larger circles meant higher intensity or importance, participants came up with their own suggestions of how one can log data. For example through the use squeeze patterns.

5.2.4 Issues, feedback, and personal preferences: "I wish it was green"

Hardware

Despite the majority claiming that Grasp felt good to squeeze, nearly all complained about the firmness surrounding the charging port. PX said, "I wish it was completely

soft, other than that it is perfect!" and PT stated, "it would be nice if the core was the only hard part, not the side as well...". Being able to squeeze Grasp from all directions was frequently requested by participants, and some complained that the hard part felt uncomfortable. A couple of participants also became aware of the "loose" core. Participants described it as feeling "hollow", and two complained that it made it less pleasant. A couple was concerned with the durability of the Grasp. PQ said it looked and felt a bit "cheap", PI described it as "flimsy", while PF was worried whether the Grasp would be able to withstand the squeeze pressure over time. PS described the overall design as "tasteful", but he also called the Grasp "fragile-looking".

Half of the participants expressed uncertainty about whether Grasp was logging their interactions, and suggested that the hardware should provide feedback. PF explained that "it is difficult to know how hard one is supposed to squeeze, a sound would be nice. My hand is getting tired because I am squeezing so hard". PS and PB wanted inconspicuous feedback through vibrations or a small light. Participants feedback does not support the suggestion from *Guribye et al.* (2016), that the compression of Grasp itself can act as a feedback mechanism . Other improvements suggested were to include a cover for the charging port or change its placement, and to add a sound recorder. One suggested including a button that you could click instead of squeezing, but this would take away the concept of Grasp.

Aside from the obvious issues and shortcomings of the equipment, participants shared a variety of personal preferences. An example is the size of the Grasp where two male participants wanted the Grasp to be bigger, and two of the female participants preferred a smaller size. Some voiced specific color preferences. PT said it would be nice if it was green and PI wanted the color to be "less blue".

Software

The web interface received positive feedback from all participants, except one, on the overall look. They described it as "professional-looking", "pretty", "neatly arranged", "manageable", and "not overwhelming". The exception was the top bar of the webpage which some found to be crammed. PQ enjoyed the monotone color scheme, explaining that it gives out a modern feel, and PX was happy to see that the color of the Grasp matched the web interface. Meanwhile, PF felt that the palette was boring, and wanted more contrasting colors. He initially described it as "looks nice, not too much going on" but changed his opinion after the think-aloud saying "a little too much going on".

Several problems with the interface were identified. PK summarized it as "the interface is more about aesthetics than usability...but it's nice that it looks professional". The issues broadly concerned the lack of intuitiveness when performing some of the tasks and inconsistency in the design. For example, when asked what they thought of the website PT said "it should have been more intuitive. Do not know what would make it better but it is hard to know which buttons to click on". Participants expressed frustration with the lack of cohesiveness across the page, and buttons "do not look interactive". There seemed to be no set standard on how buttons appear, and inconsistencies in color, size, and shape, made them hard to spot. Lack of action when hovering provided no guidance. For example, some participants mistook a blue header for a hyperlink, while some buttons were completely overlooked. PF, PS, and PT argued that a better indication as to what elements they could interact with was needed. PF said, "the color of the

button should change, or the cursor transforms into a hand". The zoom functionality of the "day by day" overview was also a source of annoyance. The absence of buttons in the data area led the majority of participants to try to zoom in by using the touchpad. When this failed some resolved to sporadically click around the data area, eventually realizing that you have to drag the cursor over the applicable part of the timeline. Even after this discovery, many struggled to select the area of interest, as there is no clear boundary between the interactive area and the rest of the background. A couple of participants could not figure out how to zoom at all. Participants argued that the interface should adhere to industry standards and that it would be useful to include "plus" and "minus" buttons in addition to the existing "reset" button.

There were mixed feelings surrounding the labeling and coloring of data. While some enjoyed additional personalization, others found that the interface and overall concept were best suited to log only one experience, making the colors redundant. Another point, that was regularly brought to attention, was the lack of interplay between different representations of the same data. This made participants unsure as to where specific actions could be performed, which resulted in unnecessary navigation.

Literature on pain-scales, tangible artifacts, and tools for health assessment shows that users often have strong and idiosyncratic preferences, both when it comes to the tools themselves and how they would like to interact with them. *Karlesky and Isbister* (2016) demonstrated the different preferences individuals have for fidget-tools, and (*da Câmara et al.*, 2018) found that children favor different interactions depending on emotional states. In the study by *Adams et al.* (2017) on smartphone pain-scales, users were influenced by design features and experienced playful interactions and aesthetic interfaces as enjoyable and motivating. It is important to consider individual differences and accommodate different users needs to encourage continued use and compliance over time.

5.3 Research questions and summary

The study aimed to investigate the rudimentary and conceptual aspects of logging experiences through squeezing and tangible interaction. One broad research question with three sub-questions was formulated before the pilot study in which our data analysis has provided some insights. The sub-questions are discussed first, followed by the overarching research question of RQ1: *How can tangible interaction through Grasp support the logging of experiences?*

1A: Can participants consistently produce squeezes of a given duration?

Participants performed well in the randomized-squeeze task, where two received a full score. One participant missed four of the prompts, in which three were *lang* and one *medium*, scoring 8 points. No other participants missed the *lang* prompt. The mean score was 10 points, indicating that patients were able to reproduce the different prompts, despite small nuances between them. This was further supported in the interviews, where most participants described the squeeze test as easy.

1B: How can visualizations of squeeze data support the assessment and reflection of experiences?

All participants mentioned that the data visualizations made sense and aligned with their physical experiences. Participants saw the visualizations as useful, and they enjoyed being able to see past interactions and trends. Recurring experiences like bad habits and stress were among the suggested use cases for Grasp. Here, visualizations could provide useful overviews for later reflection. Knowing that data could be viewed later added to the idea of distraction: squeeze to distract yourself from the craving, and later review the trends. Feedback is important and necessary to confirm user-input (*van Berkel et al.*, 2022). Although no live feedback was provided, visualizations were used to indicate how close or how far off the participants were from the intended prompts. This helped facilitate awareness and readjustments.

1C: What are participants' initial impressions of the Grasp hardware and software?

While all understood and enjoyed the relationship between hardware (squeezes) and software (visualization), participants were mixed in their reactions to the overall designs. Several highlighted issues and personal preferences, both for its physical appearance and the web interface. While most appeared to enjoy interacting with and squeezing Grasp, there were many suggested improvements such as to include on-device feedback, or make changes in the size, color, or material. Some participants would also prefer to interact with Grasp using other measures, including squeeze pressure. The interface was praised for how professional and modern it looks. Yet, several issues, including the buttons, and zooming were identified. The think-aloud results imply that the interface was easy to learn for novel users, but the interviews revealed that much work is needed for it to live up to industry standards.

RQ1: How can tangible interaction through Grasp support the logging of experiences?

Overall participants exhibited positive attitudes towards Grasp and the concept of logging experiences through tangible interaction. Squeezing and squeeze duration was well-received, and interacting with Grasp spurred a myriad of potential use cases based on participants' needs and what they thought others could use it for. The suggestions demonstrate the importance of the contextual setting for data to be meaningful, as well the versatility of Grasp. To elaborate, PX said, "the visualizations give an overview, but you need a context to make sense of it. You have to decide on what you want to log like changes over time". Interacting with the hardware and using the software was described as easy, supported by the participants' results from the two tests. Squeezing Grasp was described as natural and convenient, while the relationship between visualizations and interactions was considered logical and useful. Visualizations enabled participants to see timelines of interactions which they believed could be used for reflection. They also provided support for participants to adjust their squeezing.

There seems to be potential in using Grasp and tangible interaction, specifically squeeze duration as an input method, to log experiences - some more so than others. It was mentioned that it would be best to just log one experience at the time, and the experience should occur periodically. Interesting takeaways are participants suggestions

of using Grasp as a tool to log and later reflect on unwanted or negative experiences, for instance, stress, anger, and cravings, while simultaneously providing a distraction and a physical outlet. This may be a result of Grasp's inherent squeezing capabilities, and that it allows non-verbal, in situ logging. Children have been found to prefer objects that invite squeezing when angry, which may also hold for adults as well (*da Câmara et al.*, 2018). It is beyond the scope of this study to investigate these claims, though the data is in in line with similar literature and studies. For example studies on reflection through intentional, in situ action like the one from *Ferrario et al.* (2017), and the one on distraction through squeezing by *Tumakaka et al.* (2020) that found that children reported less pain when squeezing a ball during medical procedures. Participants suggested that Grasp could help externalize pain through squeezing which was also mentioned in the study by *Adams et al.* (2018).

5.3.1 Limitations and considerations

Several limitations must be addressed. The sampling was done through convenience sampling among university students of similar ages, and the number of participants is small which limits what inferences can be drawn. Participants all had a good understanding of technology and performed well, in spite of rating their abilities differently. It might therefore not be the case that other groups will have provided the same results. Additionally, one should be aware of the limitations of the lab setting which creates an artificial environment. Participants would probably have provided different feedback if they had had the chance to test Grasp in their everyday life and over longer periods. Furthermore, the novelty of the tool itself may have amplified participants' enthusiasm and positive feedback. Participants were strongly encouraged to openly share opinions and thoughts, but their acquaintance with the investigator, may have influenced what they choose to share.

Some limitations in terms of the equipment should be noted. One is that a couple of participants were unaccustomed to using a touch-pad and this brand of laptop, claiming that it affected their performance when navigating the website. In two instances a participant encountered a technical error during the think-aloud. Obvious errors and shortcomings like this should have been identified and fixed before the pilot. Participants were specifically asked to hold the Grasp differently than what is natural in line with its shape, which was not ideal. It is likely this has negatively affected participants' experience with Grasp, as they often expressed the desire to hold it differently, and some experienced discomfort when squeezing it over longer periods. The same goes for the issues with the material and the loose core. Ideally, the prompts used in the squeeze test should have been more similar to each other, i.e. with equal intervals.

5.3.2 Summary

Existing studies on tangible interaction focus on squeeze strength. Eight students took part in the pilot study consisting of a think-aloud task, a squeeze task, and a semi-structured interview. Participants have shown that it is possible to use squeeze duration as an input method, even when margins are small. Some of them even expressed a preference for using squeeze duration over squeeze pressure if given the choice.

Grasp was generally well-received, and the majority of participants thought it had potential as an alternative way of recording experiences or everyday events. They enjoyed interacting with it and shared ideas on how it may be used. For instance, some thought that Grasp could be used as a distraction or to externalize anger. The mapping of squeezes to visualizations was perceived as meaningful, logical, and intuitive. Visualizations were especially useful in the learning phase as they provided feedback on the participants' interactions, helping them adjust themselves. Several issues with the accompanying interface were identified and should be considered when further developing the platform. All in all, participants varied in their individual preferences regarding both functionality and design of hardware and software, and how they would have preferred to interact with the tool. These are important to consider ensuring adherence to the tool over time. The results coincide to some extent with similar studies in which participants also expressed that squeezing was natural, but they wished the device provided feedback (*Adams et al.*, 2018)

Participants' experiences on the overall design, concept, and feedback are useful to further develop Grasp or similar tools. The data also add to the literature on tangible and non-verbal logging, suggesting that there is potential in studying the use of squeezing as an input method further. Participants' feedback also suggests that Grasp can support affective interaction, but this requires further examination. Despite the small number of participants and the limitations of the study, the results bring new insights on how one may use squeeze duration to log experiences.

Chapter 6

Clinical Trial Data and Results

In the following chapter, the data and results from the clinical trial are presented. An introductory section based on the nurses' interview data is provided to help set the context of the study. Then attention is given to the questionnaire data from patients and nurses, succeeded by a thematic analysis. Seven themes were identified: "current practice, everyday barriers and ESAS-r", "overall experience", "patients struggle with numbers", "different tools with different pros and con", "visualizations that support reflection and communication", "disease related patient barriers", "grasp has potential but not for all", and "changes takes time".

6.1 The cancer ward

The cancer ward examines and treats patients with a wide variety of cancer and hematological diseases. The majority (nurse estimated 90%) of the patients receives palliative care. Patients diagnosed with gynecological cancer, lung cancer, or ear-nose and throat cancer are primarily treated in their respective wards. However, patients with an especially complex clinical picture or those requiring palliative care are sent here regardless of their cancer diagnosis. The ward encompasses three bed clusters, accommodating a total of 26 patients at a time with an estimated 6-12 patients admitted and discharged every day. A *bed cluster* (sengetun/tun) is a smaller number of beds, often seven to nine, placed in single rooms around an open work-station for nursing staff (*NAOB*, n.d.). These clusters are designed to shorten the walking distance for nurses and make it easier for them to care for patients, prevent undesirable incidents and save time as compared to the traditional corridor layouts (*SINTEF*, 2013).

The average length of patient hospitalization is 3.9 days, though most patients stay for even shorter. The ward employs 85 people in positions of varying types and sizes. It is supervised by two Heads of Section, both of which are nurses with over 40 years of combined experience in the field. They oversaw the practical execution of the trial, and have been an invaluable resource. The Heads of Section are in charge of a wide variety of tasks including handling daily operations, budget, logistics and coordination related to patients and employees. They further ensure that the ward is being run in a sound manner, and that the employees are well and looked after. Although the two have less patient contact than the other nurses, they engage and care for patients when needed and take charge in cases of emergency. One of them expressed "one has a heart for

cancer patients, so you get a little involved ... still a little bit with the patients, you want to keep the discipline up and running ...". She further explained that patient contact had increased during the clinical trial "now it has been a little more as I have been involved with Grasp, because then I have talked to them a little more ... A little more in-depth ..."

Days at the cancer ward are varied and change depending on patient-related causes. A fixed event is the *doctors' round* (*legevistt*), a daily and systematic update and discussion on patient care by bed cluster. In the morning, the attending physician, doctors, and the cluster-responsible nurse go through the reports of each patient from the night before. Patient measures and interventions are discussed. If any ESAS-r scores have been recorded, they may be brought up. Afterwards, a visit to each patient in the cluster is performed.

Nurses tasks and routines depend on their assigned role for the day as either *innesykepleier* or *utesykepleier*. The *innesykepleier* or cluster responsible nurse oversees the bed cluster by distributing medications, communicating with the municipality or other health care institutions about scheduled patient discharges, and order needed medical appliances (*behandlingshjelpemidler*) for continued at-home treatment or palliation. The latter role is centered around direct patient care and includes typical procedures such as sterile procedures, mapping of patient symptoms, providing meals, as well as collecting patient measurements (blood pressure, temperature, and pulse). They also administer ESAS-r forms, where the stated procedure is to apply ESAS-r when patients are admitted and discharged from the ward and at least twice a week during their stay. For patients with severe symptoms, ESAS-r should be administered daily. Nurses should do this by bringing a pen and paper ESAS-r for the patients to fill out. If the patient is unable to do so by themselves the nurse may assist. The answers to the completed form should then be typed into the digital journal system, DIPS, where patients' past scores can be seen in a tabulated format.

6.2 Questionnaire data and results

6.2.1 Patient questionnaires: ESAS-r and Grasp

Summary data of patients' experience of ESAS-r were collected in Phase 1. 26 patients completed the ESAS-r questionnaire, and out of 156 possible data points, one is missing. In Figure 6.1 a complete overview of the questionnaire data is presented as a centered stacked bar chart. The same type of chart is used for Grasp data in Figure 6.2.

By examining the first four bars, Q1-Q4, one can see that the data is quite evenly distributed with each of the graded response categories present. The data is further centered around 3 (*some degree*). This is confirmed by finding the median and mode. An overview of group statistics is included in Table 6.1. For all four questions the number of patients answering 5 is slightly higher than those choosing 1. For instance, three patients believed that ESAS-r had been very helpful in gaining an overview of their symptoms, one patient answered that it had only been helpful to a *very small degree*. For Q2 "to what degree do you think the form has helped you communicate your symptoms to your doctor/nurse?" 35% of patients answered 1-2, 38% answered 3, and 28% answered 4-5. The majority of patients experienced ESAS-r as at least somewhat helpful,

i.e. answering ≥*some degree*, in gaining an overview of their symptoms (73%), communicating their symptoms to their nurse/doctor (65%), partaking in decision making regarding treatment (62%) and being confident in the treatment they receive (69%).

Looking at the last two questions Q5 and Q6, the data is visibly leaning towards the lower values. Q5 is a negatively charged question and has a mode and median of 1. 64% of patients answered that the degree to which ESAS-r had increased feelings of uneasiness surrounding their symptoms was small. Contrastingly, 12% experienced that uneasiness increased to *some degree*, and one patient believed that it had increased to a *high degree*. To Q6, four patients answered that ESAS-r was very helpful in communicating symptoms to relatives (16%), but the majority believed the effect was small (50%). Q3, Q5, and Q6 all had some respondents answering *not relevant*. The same trend was seen in the Grasp questionnaire, here also for Q4. The data does not provide insights as to why this is the case. It could be the result of patients not staying at the ward long enough for visitors to come by, or for them to partake in treatment plans (Q3, Q6). Another plausible answer is that the questionnaire does not provide a *no degree* answer. Five patients from ESAS-r and two from Grasp answered *not relevant* to Q5 "to what degree has the use of the form led to increased uneasiness surrounding your symptoms". One patient in both the ESAS-r and Grasp questionnaire left Q5 blank. In light of this uncertainty, the number of *not relevant* answers are not treated as missing values and are included in the total number of responses.

The ESAS-r questionnaire did not provide any open-ended questions. One patient still included a comment saying that "I did not think of the form as a form of reflection when I filled it out. Let the patients read this form once before filling in all the other so that the brain is put on the right track". It is unclear whether the patient is referring to the ESAS-r symptom form or the ESAS-r questionnaire. As this patient answered all questions with *small degree*, one might reason that the patient is referring to the latter.

In Phase 2, summary data of patients' experience of Grasp were collected from eight participants. All patients were palliative cancer patients using Grasp to log their pain. In total, 44 out of 48 graded data points were gathered. One patient left four questions blank, and added a comment saying that "I think the period of use has been too short to give a full-fledged evaluation". From initial examination of the bar chart, the data from the Grasp questionnaire appear to be similarly distributed to the one for ESAS-r. For Q1, Q2, and Q4 the median and mode are 3, identical to ESAS-r, indicating that the data is centered towards the middle. Patients generally experience Grasp to be at least somewhat helpful, ≥3, in gaining an overview of their symptoms (88%), communicating them to their nurse (75%), and being confident in the treatment they receive (85%). This is higher compared to ESAS-r. A notable difference to the ESAS-r data is that no participant answered *very small degree* to any of the four first questions about Grasp. For Q4, all answers fall into either *some degree* (71%) or *very large degree* (14%). In contrast, these categories make up 31% and 15% respectively for the equivalent ESAS-r question. Here 31% of patients answered ≤*small degree*, and 23% answered *high degree*.

The median and mode for Q3 are 2,5, and 2 respectively, slightly leaning towards the lower values. One patient answered that this question was not relevant which affects the overall percentages substantially. The equivalent ESAS-r question had a median and mode of 3. Yet, two patients reported that ESAS-r had only helped them communicate their symptoms to their nurse to a *very small degree*. No patient reported this

Figure 6.1: ESAS-r Patients Questionnaire data in a stacked bar chart with numbers and percentages calculated from the total number of responses (N). A green N indicates that all patients answered the question. Red means that some left it blank. Not relevant *responses are not visualized but presented by the number of answers and percentage on the right hand side.*

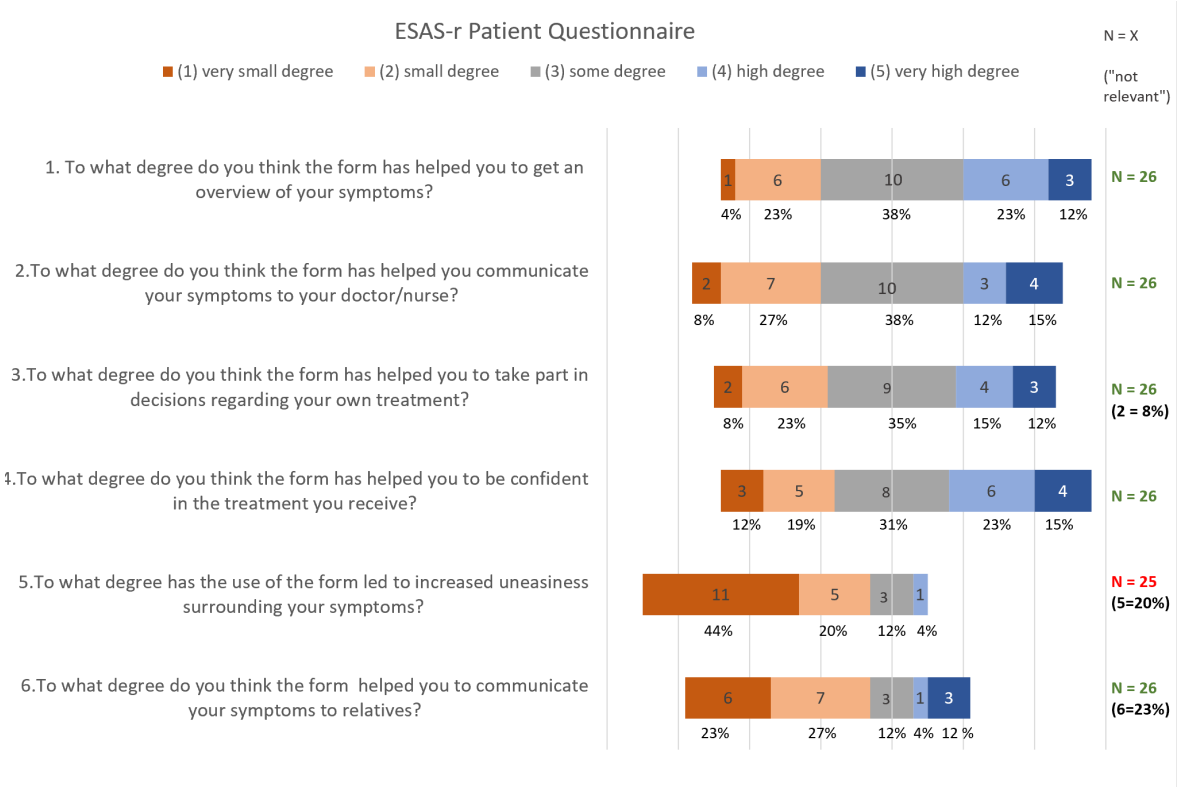
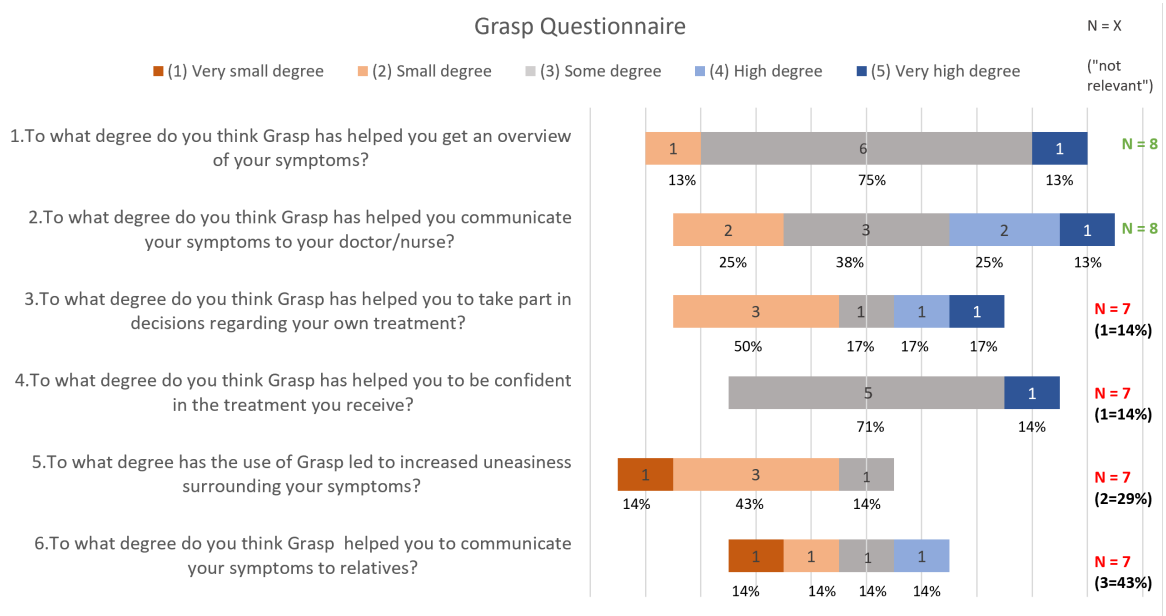


Figure 6.2: Grasp Patients Questionnaire



for Grasp. Q6 also has a median of 2,5 but no mode as each category received exactly one response. For Q5 the majority of patients believed that the use of Grasp had only increased uneasiness surrounding symptoms to a *very small* or *small degree*. Not one patient reported that it had increased uneasiness by more than *some degree*.

Relationship between ESAS-r and Grasp

Initial investigations highlight only small differences between responses to ESAS-r and Grasp. The uneven number of responses between the phases makes direct comparisons difficult. Grasp and ESAS-r, despite their similarities as symptom assessment tools, are inherently different in several aspects. This should be kept in mind. A Mann-Whitney U test with a 0.05 level of significance was performed to further examine this relationship. $H0$ states that there is no difference between patient responses to ESAS-r and patient responses to Grasp. $H1$ states that there is a difference between patient responses to ESAS-r and patient responses to Grasp.

The MWU test indicates that there was no significant difference in responses between the patients using ESAS-r and those using Grasp for any of the dependent variables, Q1-Q6. An overview of the test statistics is included in Figure 6.1. To elaborate, the first row the table shows that the MWU test revealed no significant differences in the responses to Q1 of patients using ESAS-r (median = 3, N = 26) and patients using Grasp (median = 3 , N = 8), U= 100,500, p > 0,05. We, therefore, fail to reject the null hypothesis, and our data is insufficient to conclude whether observed differences are due to chance or not. Having said that, the patient in Phase 2. was also subject to ESAS-r. Although the questionnaire only enquired about Grasp, this may have affected their experience. The results might be interpreted as Grasp in combination with ESAS-r performing equally or similarly to ESAS-r alone. Or most importantly that it did not perform significantly worse. This is a meaningful inference as ESAS-r is the recommended form for palliative and has been subject to several studies. One might ask why no significant differences were seen. The results are susceptible to faults in the study design (small number of participants, length of study, and practical execution), as well as assumptions about the tools and how patients and nurses would use them. Some of these issues are highlighted in the thematic analysis.

Table 6.1: Group statistics of ESAS-r and Grasp.

	Tool	N	Mode	Median	Mann-Whitney U	p
Q1	ESAS	26	3	3	100,500	,889
	Grasp	8	3	3		
Q2	ESAS	26	3	3	112,500	,352
	Grasp	7	3	3		
Q3	ESAS	24	3	3	69,000	,900
	Grasp	6	2	2,5		
Q4	ESAS	26	3	3	84,000	,796
	Grasp	6	3	3		
Q5	ESAS	20	1	1	63,500	,371
	Grasp	5	2	2		

Q6	ESAS	20	2	2	43,500	,794
	Grasp	4	N/A	2,5		

Additional Grasp questions

The Grasp questionnaire contained an additional five statements about the patient's experience with Grasp. A bar chart of patient responses appears in Figure 6.3.

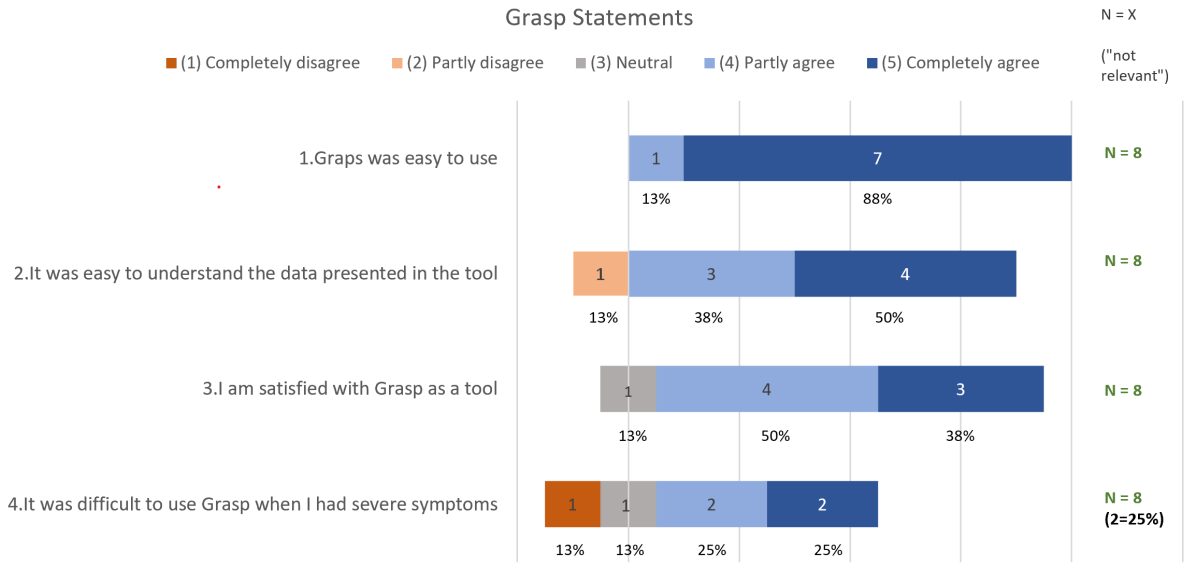
Grasp was considered easy to use by all patients, where 88% answered *completely agree* to Q1. Half of the respondents believe that the data presented was easy to understand, while one patient thought it was somewhat difficult. When asked if it was difficult to use Grasp when experiencing severe symptoms (Q4), answers varied. Half of the participants *agreed* or *completely agreed* that it was hard to use Grasp when experiencing severe symptoms. One patient (13%) completely disagreed and one was neutral. A comment from the open-ended questions highlights the impact of severe pain. One patient wrote that Grasp was exciting, but that one already had enough to think about when experiencing severe pain. Two patients notably answered Q4 with *not relevant*. Perhaps they did not experience any severe symptoms during the trial? Looking at their overall experience with the tool participants expressed that they were satisfied with Grasp (88%). This was highlighted in the qualitative data. Five out of six responses to "what do you think about using Grasp?" included positive feedback on Grasp. One patient said "brilliant! It made it easier for me to contact the staff for palliation after I started using Grasp". Another patient said, "it can be a great tool over time". While the other patients described Grasp as "exciting", "easy to use" and "I think it can help to use Grasp", two mentioned that the trial period had been too short to provide proper feedback. For the final questions asking if there was anything particularly good or bad with Grasp, one said that Grasp was easy to use. Another explained that "it is sometimes difficult to identify the pain, and therefore hard to know when or how hard I am supposed to squeeze". This emphasizes some of the challenges of individual pain experiences.

6.2.2 Nurse questionnaire: ESAS-r and Grasp

Only four out of seven nurses, all female, answered the final assessment form about their experience with ESAS-r and Grasp. Answers to the open-ended questions have been combined with the interview data. This leaves four graded questions comparing Grasp to ESAS-r (Q1-Q4) on a scale from *very small degree - very high degree*, and seven graded statements about Grasp (S1-S7) on a scale from *completely disagree - completely agree*. One nurse left all seven statements blank, and another nurse failed to answer one question, resulting in an even small dataset. The final dataset encompasses 36 out of 44 possible responses.

When asked to what extent Grasp provided a deeper understanding of the patient's disease picture compared to ESAS-r alone (Q1), two nurses answered *high degree* and two answered *some degree*. Similar answers were provided for statement S3 which says "Grasp gave me useful information about the patient's disease picture", where two partly agreed, and one completely agreed. Q2 asked, "to what degree did Grasp provide a better overview of patients' specific symptoms compared to ESAS-r alone?". To

Figure 6.3: Grasp statements from patient questionnaire.



this question two nurses answered *high degree*, one *very high degree* and one answered *some degree*. This indicates that nurses may benefit from using Grasp. The same distribution of response categories was seen in Q4 "to what degree did Grasp help improve communication with your patients, compared to ESAS-r alone?". Interestingly, one nurse answered *some degree* to Q1-Q3, but *high degree* to Q4.

Different answers were provided by all nurses for Q3 "to what degree did Grasp make it easier to implement the right treatment and measures, compared to ESAS-r alone?". The nurses replied with options 5, 3, and 1. For the related statement S7 "the use of Grasp has made it easier to make clinical decisions than just ESAS-r" two nurses answered 3 (*partly agree*). One replied that Q3 and S7 were not relevant. Among the three nurses who responded to the Grasp statements all answered *completely agree* to S1 "the visualizations of Grasp were easy to understand" and S2 "Grasp was easy to use". When asked if they were satisfied with Grasp as a tool (S4) two answered *completely agree* and the last *partly agree*. A generally positive trend. However, two of them partly agreed that it has been difficult to implement Grasp in the daily routine, while one party disagreed with this statement (Q6).

Altogether, the questionnaire data implies that while there are some trends in patients and nurses experience and opinions of ESAS-r and Grasp, there also seems to be individual differences. Nurses' experience and their observations of patient opinions are clarified and highlighted during the interviews.

6.3 Thematic analysis

Rich insights about the cancer ward with its patients and employees were provided by the four nurses (N1-N4) who partook in the semi-structured interviews. They openly shared experiences and observations from their interaction with patients and the tools. Nurses' professional experience ranged from 4 to 23 years, and their heartfelt care and passion for the patients were evident. This section starts with a summary of the current

practice at the ward and everyday barriers, followed by a description of nurses experience with the overall trial. The seven themes, some with sub-themes, are presented beneath.

6.3.1 Current practice, everyday barriers and ESAS-r: "they have not understood the point of using it..."

The biggest challenges in nurses' work days ranged from not enough time, logistics, and lack of staff. Unforeseen events and patients with challenging clinical pictures contribute to sudden changes, reprioritization, and accumulation of less urgent tasks. This may again contribute to nurses' distress. N4 said that when unforeseen things happen "you have to do that, and something else has to be put aside...you have to find a balance you can be happy with...". N2 added that "logistics can be a bit tricky ... we have challenging cases which can be mentally draining... but it is a part of the job". Nurses look out for each other, and humor has become an invaluable tool as N3 shared "while there can be tough days, we have very nice colleagues ... And we laugh a lot..."

The interviews confirmed that ESAS-r was not an established tool in the ward, and nurses' familiarity with the form before the trial varied. N3 said, "honestly, we have been really bad at it [ESAS-r]...", and N1 expressed that "I heard about it, but never really understood what it was, and then I got to know what it was and realized that we have to do this daily...". Only one nurse applied ESAS-r regularly before the study. N2 described ESAS-r as the "only scale I have to tell me how approximately the patient is feeling...how else am I supposed to know how efficient the measures implemented are, and recovery?". She would bring a printed copy along to show the patients as she made her rounds explaining that

> I always come in [to the patient] in the morning and present myself and then to take measurements ... Then I usually ask about how the night has been so that I know if it has been a good night or a bad night "what has been bad? "Have you been to the bathroom a lot?"...I have some things I like to ask about in the morning so that I have control, and so that I can implement measures relatively quickly if necessary...

She explained that all nurses have their routines and that patient's responses give her an indication of how to proceed with the day. It was revealed that she did not input the results into the journal system, which would have made them accessible to the other nurses, saying "It has rather only been for my own mapping and my reporting to the doctors so that they know what to prescribe...". Nurses who did not utilize ESAS-r regularly emphasized that symptom assessments always took place through observations and conversations with the patients. N3 would ask "do you have pain? have you slept", focusing on the presence of symptoms rather than numeric intensity. N4 said "we do ESAS-r but without the numbers, and that is a little unfortunate that it turned out like this...". She admitted that a lack of systematic screening could be problematic as less concrete documentation was gathered.

Nurses are trained and skilled in their profession, yet they might fail to recognize patients pain and accordingly misjudge their pain intensity when relying on their own observations (*de Rond et al.*, 2000). Stigmatized symptoms like anxiety may also go

unnoticed "it may be that the ESAS-r form would have provided such a natural opportunity and in a way talk a bit about it..." N4 added. N1 shared that "the nurse and the health professional know everything that is on that form in the first place, but they have not mapped it in a form ... " She further said, "it is great with forms, but we need to ensure it does not become a "form world" [*skjemavelde*]. That the clinical view and what we do disappears...".

Reasons why ESAS-r had not already become a part of the routine, were multifaceted. Nurses described issues including lack of time, workload, short patient hospitalization, patients finding it difficult to use, lack of knowledge about it, and that nurses did not see its value. "I know that 80% of the ward did not know about this from before, that it [ESAS-r] was supposed to be used. Because they have not received training in it. And they have not understood the point of using it..." N1 said. N4 expressed:

> I do not know exactly when it was dropped. We have a procedure...some patients find it difficult, and then also in a way not all nurses and health professionals understand the point of it or see the benefit of it...because you have so many things to do...

Howbeit, she disagreed with N1 that nurses did not believe it was useful. N4 hypothesizes that it was a question of priorities and that because there were so many other things that were important. She also pointed out that the nurses and doctors had to collaborate for ESAS-r to become meaningful: "I have taken an ESAS-r and there are high numbers... if the doctors do not follow up... then it is like 'why should we do this because we do not do anything about it?'".

6.3.2 Overall experience: "fun but a lot of work"

Nurses were positive about the overall trial and introduction to Grasp describing it as "fun, interesting" and "exciting". N3 said "really great! ... and fun to do something else and something new, it is not something like this that I usually do...", and N4 explained "it has been very fun to be a part of something completely different ...". N2 was initially skeptical of the incorporation of Grasp saying, "I have to be honest and admit 'ahh another thing!' ". She then decided she should give it a chance "one is always open, willing to change ... I thought 'yes, it will be exciting to see if it has any use then' ". When asked to share her thoughts now that the trial was over, she said that Grasp was intriguing and an interesting concept. Even so, she was unsure whether the patients that were included in Phase 2. had been the "right ones" to use Grasp. Although positive, nurses emphasized that there had been a lot of extra work and effort to incorporate and convince the rest of the staff to use the tools. N4 said, "it has been a little exhausting, but that is just because I feel like everything that is new takes a long time to incorporate". ESAS-r was applied to all nurses, and while it required a lot of nagging, N4 did not experience "that much" resistance. Grasp was only used by those who agreed. N4 always had to be positive and try to engage the other but added that

> at the same time it has been fun because ... like it is easier to talk positively about something when it is something you believe in yourself... it requires a bit of an extra effort from me...so precisely because I see that it is a good product [Grasp] and that it can do something for the patient, and I see that,

> a couple of the patients think that it has been exciting to be a part of, and that does that "well, then I spend the extra time"

When asked how it went to use Grasp every day, N2 said that it was not a big job. She also admitted that she had not sat down with the patients to discuss their data, as the other nurses. She did bring it along for the doctors' round. As there was not always time to look for patients' information in the journal system, the iPad became handy, and she could easily show the visualizations. One hindrance in introducing Grasp was that ESAS-r was still an unfamiliar procedure. N1 shared that as long as ESAS-r was not properly incorporated in their routine everything else just became extra work, and Grasp became a question of nurses' individual interests.

Three of the nurses were engaged in the trial from the early phases, allowing them to evaluate Grasp and voice their needs and wishes giving them a sense of ownership. N1 said, "we have been part of it the whole way ...in collaboration with the others we have come up with ideas, thoughts around it [Grasp]...". N4 enjoyed partaking in the development of a tool that should be "as easy as possible to use, and then require as little as possible from the employees, and that you can see that it is time-saving ...". She shared that she felt that her feedback was taken seriously, and that being acknowledged gave "an extra boost". The challenges faced in using Grasp were mostly software-related and easily overcome: "it is not a finished product, but that being said they [Grasp team] fixed the issues lightning fast... that makes you want to continue...". One concern that was frequently mentioned was the duration of the study had been too short to see clear effects of either tool. "Because patients do not stay with us for long ..." N4 said. This was also seen from the patients' questionnaire responses. Participating nurses faced several barriers in recruiting and engaging other nurses and finding appropriate patients for the second phase. Change takes time, and nurses believed that the outcomes of the trial would have been different if the project had started when it ended.

6.3.3 Patients struggle with numbers: "the worlds' hardest question"

Nurses reported that patients seemed to understand ESAS-r and what it was. While some were able to fill out the form themselves, many require extra assistance which takes time in a busy workday. A persistent issue was patients struggling to answer the questions, and they felt bothered by the repeated assessments. N1 explained "the trend I hear the most, that they [patients] do not understand and in fact are sick and tired of them [nurses] asking about it...'I have pain, why do you ask about nausea?'". N4 and N2 shared similar insights and said that the patients struggled to see the implications of ESAS-r. The last nurse believed that patients saw the value of ESAS-r especially as it helped foster communication between patients and nurse staff. She did not hide the fact that patients struggled to put a number on their condition. Patients' reactions to daily ESAS-r were often "oh you are coming with that form again...". N2 illustrated the issue by saying "on a scale from 0 to 10, there is no more difficult question than that, for what is the world's, what is the biggest pain imaginable?' " She further stated that "if you have constipation then it becomes all-consuming ... but maybe not a 10". It is crucial that patients are assessed and inquired about their symptoms in language they understand (*Shoemaker et al.*, 2011)

Patients often had a lot on their minds, and they started talking around, overthinking, or complicating their answers when faced with difficult questions. They considered all the aspects of their symptoms rather than the intensity: "yes but this type of pain... but that is the worst imaginable, not but I am not close to death". Knowing that the scale had an upper limit seemed to affect their reasoning. N2 stressed that some patients had severe symptoms constantly, but that rating oneself as a 10 was perceived as drastic "excruciating pain...then it must be quite awful?". The issue of unidimensional numeric scales and individuals personal preference was highlighted in the related literature in Chapter 2.

6.3.4 Different tools with different pros and cons: "it is not comparable"

Despite being easy to learn and use, at least for nurses, opinions on ESAS-r were mixed. N1 did not think it was a good tool as it only provides a glimpse of the patient's condition. She said that although the form had some good qualities, applying it once a day was inadequate for it to be useful. N3 had noticed patients struggles to answer the form and the limitations of its nature. She recalled a patient saying, "yes I am doing well now, but ask me again later and you will see I am not well on any of these [symptoms]". On the other hand, ESAS-r had also made room for conversation and for patients and nurses to sit down together. N3 believed that patients felt more seen when they had the chance to chat. Other nurses also expressed the importance of talking with the patients. N2 said, "who just hands out a form for [patients] to fill out and then just collect data? You have to talk about it. 'I see that you have squeezed, or that you checked this here, can you tell me more?'". For her ESAS-r was used to confirm her observations saying, "it is just numbers, but then you have to see if they coincided with what you would expect from pain on 10 versus 0". For N3 the form had helped her remember to examine all symptoms: "I think that it is good, at least the best we have right now. But it is a snapshot... [their condition] can have changed just from going to the bathroom". N4 generally thought that ESAS-r was good and that it painted a picture of the patient, although just momentarily. She acknowledges that scores could give an inaccurate assessment of patients' overall well-being.

When it comes to Grasp, the four nurses answered unanimously that it was easy to learn and use. N1 said "I do not get those who do not get it", and N2 expressed "it is not like it is rocket science..." before adding "or um, maybe that you are open to change. That you try to have an open mind". N3 shared that it had been easy for her, but that people are different, and N4 described the learning process as " it was so simple that there were not any problems, the problems came when I tried to teach it to others and then met a little resistance, or not resistance but...". The visualizations were also deemed easy to interpret and use. N1 one was particularly happy and said "very simple! I used the app mostly, and I think it is totally transparent and easy to understand...". She mentioned that although there had been some initial difficulties they were resolved once she became familiar with the system. One said, "it has been pretty good, and I think the patients thought that as well. There is something about seeing your squeezes...".

Nurses experienced that patients had no problems in understanding Grasp, and they were positive towards it. "Most get it...in a way, you could not have made it any eas-

ier than squeezing that ball...", N3 said. Patients did not show the same reluctance with this tool compared to ESAS-r, but they had to be reminded to use it because it was something new and easily forgotten. Challenges of the adoption of Grasp principally involved patients not squeezing the ball. One of the nurses said that it is good they understand the concept, but they must also use it correctly. She observed patients squeezing it frequently, but if their symptoms turned severe, they put it aside. Patients questionnaire answers support these findings. N3 added that a few patients were too weak to squeeze it and failed to produce data. In rare cases, nurses were unable to disclose why the patient had failed to use Grasp even after asking them repeatedly. N1 said "we have perceived that they have understood it but then they have somehow not squeezed it anyways... I have not been able to figure out why ...". She illustrated a curious case with a female patient who was deemed clear-headed. When confronted with why she had not used Grasp when she experienced pain, no good answers were provided. The nurses had suggested they stop using Grasp, but the patient refused. Another concern was that Grasp was "another thing" the patients had to carry with them. Yet, the nurse who shared this issue said that " a diabetic can do this very well with taking his insulin pen or a blood glucose meter ...if you say for a period ... then I do not think it is a problem too, especially not inside a hospital ward...".

A snapshot or an overview

When asked to assess Grasp in relation to only using ESAS-r all nurses commented that Grasp provided a wider image of patient symptoms. As patients could use the Grasp without nurses being present, data could be collected during day and night. N1 said "the data you get from Grasp is much more informative. For me, it is not comparable because with the one you only get a snapshot, and with the other, you get a daily picture...". N4 believed Grasp could be a useful addition to ESAS-r and form a holistic 24-h image of the patients. She mentioned how the guidelines of using ESAS-r twice a week often would produce low scores, and that patients sometimes were discharged after one assessment. The issue of infrequent and even inadequate patient assessment is a common concern in hospital wards (*de Rond et al.*, 2000; *Price et al.*, 2018). By utilizing Grasp, the nurses could pick the most severe symptom as identified by ESAS-r and work on it until it became less urgent. They could then, in theory, move on to another symptom. N4 exemplified that if a patient scored low on ESAS-r one would think that the patient was doing okay. You could then give the patient a Grasp overnight, and in the morning, you might see, "'wow shit you squeezed ten times yesterday, you were not doing so well? 'no, after you left I had pain' ".

Other nurses noted that Grasp might be less burdensome to the patients as it only assesses one symptom at a time and does not require choosing a number. They can simply squeeze. Yet, this could also be a shortcoming. One nurse remarked that Grasp does not depend on language, except for the initial explanations. She suggested that this could help address some of the barriers of assessing symptoms with foreign patients.

6.3.5 Visualizations that support reflection and communication: "you squeezed a lot"

The visualizations helped nurses in drawing inferences and assumptions about the patients. A couple had used Grasp data to confirm or remind the patients of their experiences and to spur conversation. It also gave insights into less expressive patients and their symptom fluctuations. A nurse explained that when she noticed a lot of squeeze data from the evening before she might assume that the patient would be tired the following day. Others would use the data to confront the patients: " here you squeezed a lot during the night ...you have not received analgesic; you did not tell us". N3 described that "because you do not know what goes on behind closed doors...and patients are reluctant to notify staff, Grasp had led to good conversations where patients got to "see themselves" through visualizations. In the study on Painpad, a tangible NRS-11 for patients self-reporting of pain, patients expressed interest in monitoring their pain over time to support reflection (*Price et al.*, 2018). One patient even mentioned that a day-to-day chart would be helpful.

Patients have a lot on their minds and are sometimes forgetful. They need a reminder of what they have experienced. By showing them their data, they got a clearer image of their symptoms. When data were collected, nurses were able to ask about it and go into details of what had happened when they were not present. Patients might say "yes, yes but that is true I did not have a good night yesterday", when nurses showed them their data. Grasp data also helped materialize and confirm the patients' experiences to the doctors. One patient claimed that he experienced pain every time he would eat, which was confirmed by his squeeze visualizations. "And then we [nurses] saw the day after that yes, so we kinda saw the timestamps that indeed, that was the meal ... so we could kind of visualize it and confirm it to the doctor that 'look here you, he has squeezed at the times that he said'", N4 elaborated.

6.3.6 Disease related patient barriers: "they want to be healthier than they are"

General symptom assessment is affected by several patient-related barriers. There are great differences between patients in terms of their clinical picture, demographics, and their physical and mental state. The average length of hospitalizations is short, patients are often repeatedly discharged and re-hospitalized, and death is not uncommon. Some patients can partake in discussions regarding their condition, but this is not the case for all. The ward also has several foreign patients where language poses a barrier. Together with large and unpredictable fluctuations in patients' symptoms and individual needs, symptom assessment can become a challenging task.

Pain is a common symptom but patients' symptoms can be "everything. It can be nausea, it can be pain ... impaired general health, infections...". Depression and anxiety is common with this patient group, and symptoms often go hand in hand with each other and treatments, forming an evil circle if not properly attended to. N4 exemplified that patients may experience pain from obstipation which is a result of analgesic. She further said:

> we also use a bit of sedative... not necessarily for anxiety, but for restlessness and 'many thoughts'...sometimes when they have a lot of pain, instead of distributing analgesic we give them something to help relax and then we see that it helps. And then, the pain actually originates from them being scared

Patients' clinical picture shifts frequently. Upon admission to the ward some can recover quickly while others experience a rapid decline in health. Cases like this are demanding for patients experiencing a range of symptoms and emotions, and nurse staff trying to provide care and comfort. N1 described it as:

> it varies just from the start of the shift to the end. One patient can lie down under the duvet and refuse to talk to you when you come to work, and then at two in the evening, afternoon... then it's 'hello!' and everything is great again, right? So the mood level can go from zero to a hundred..

Some patients are too ill to be assessed through conversation or standardized methods. Nurses adapt their routine based on the patients' condition and how far they have come in the course of the disease. With very ill and terminal patients "it is a little more calm. There we might have stopped taking measurements ... we do not shove things at them as much. A little more according to their pace and desires..." N3 said. N2 stated that as long as patients could account for themselves it was easy. If not, nurses relied on their clinical gaze and experience.

Other patient barriers include underreporting of symptoms, misconceptions about analgesics, and patients' fear of being a nuisance. Occasionally denial and fear of being too ill to receive treatment are observed. N1 said, "I see a couple who underreport their pain, and that is, I guess because they want to be healthier than they are... ". N2 shared that underreporting occurred in all demographics, but some more than others: " very often the ones who are older are more skeptical of analgesics, right? And they think it is hard to explain how much pain they have. And they are skeptical of implementing measures". Nurses feared that some patients may score low on ESAS-r to prevent being a nuisance: "I am sorry for being admitted and that I am a little sick". One shared that patients were generally good at reporting symptoms, like nausea, that are not taboo and easy to talk about. Per contra, patients are reluctant to report depression or anxiety as "some may think it is embarrassing...". Nurses emphasized that for ESAS-r and Grasp to be useful patients have to be honest about their symptoms. Patients would occasionally rate their symptoms differently than nurses would expect. N3 said, "I see a person who is lying and almost unable to open his ... and then scores himself 0 on drowsiness ... ". Though this at times was a result of denial, N3 disclosed that patients can exaggerate their health because they must be somewhat well to receive treatment. This becomes an ethical concern when the nurses and doctors want to end treatment that may cause more harm than good, but the patients dearly wish to continue. The many challenges and barriers identified are consistent with what is reported in similar literature (*Francke and Theeuwen*, 1994; *Nayak et al.*, 2015). Nurses must balance patients' individual needs with the confinements of a clinical environment and ethics.

6.3.7 Grasp has potential but not for all: "not the most unwell and the very oldest"

All the participating nurses believed that Grasp had the potential of becoming an asset, but not for all patients. They shared that it should generally only be used for one fluctuating symptom at a time, and once this symptom was treated and under control, the patient could apply it to something else. N4 said that it would be valuable for "patients with pain challenges, that for some reason will have an escalation in pain". One of the patients could clearly identify her pain into two different types. The patient and the nurse agreed that she should squeeze Grasp differently for each type. However "she was not quite able to do the squeezes, then some other things happened and she underwent surgery...". It might not have worked as envisioned, but it demonstrates the important process of patients and nurses deciding upon how data should be interpreted. It also shows that the system does not confine the users by predetermining and categorizing data. Parallels can be drawn to the feedback from the pilot study that Grasp was most suitable for one experience at a time, that the meaning and context had to be decided, and that different squeeze patterns could be used to log nuances.

Another patient that was initially considered for the study was excluded after sharing that he was in constant pain and as a result did not know when to use Grasp. Similarly, a nurse with a knee injury applied Grasp to herself and realized she had pain every time she walked and that it did not make sense to log it. She said, "if I had pain that came and went, I would undoubtedly use it and then bring it to my doctor 'here is my challenge, this is what my pain problems look like'...". This way Grasp could help provide "proof" of sometimes invisible symptoms and help log them in between doctors' appointments. She remarked that it was difficult to answer her doctor's typical questions about when and where her pain occurred - a well known issue. "I think this is something that could make the patient feel more taken care of. If the doctor gets it and understands and see what I have logged." This way Grasp would function as a transitional object between the patient and the doctor, as it was designed for *Guribye et al.* (2016).

One nurse thought it could be interesting to use Grasp for anxiety: "maybe we should go a little deeper on that anxiety part. But that requires preparations, a chat with them, and that they in a way can admit that they have this sort of problem...". As many patients were reluctant to share their anxiety, squeezing Grasp could help convey their experiences to the nursing staff inconspicuously. Similarly, another nurse mentioned "I have a neighbor that was here [in the ward] with us before this [trial]. And she is very bothered with anxiety, and I think she would have been a fantastic candidate to use Grasp...". The neighbor was not as advanced in her cancer disease as some of the other patients in the ward. Nurses conveyed that the patients included in the trial might have been too far down in the cancer trajectory for them to benefit from Grasp. That being said, ESAS-r was also not applicable to very sick patients. One said, "It may be that some of the patients we have are too ill...". She suggested that Grasp should be introduced to patients at an earlier stage enabling them to partake more and document their symptoms to gradually create a picture of their medical history. (*Torvik et al.*, 2014) also found in their application of ESAS that tools must be introduced to the patients during the early stages of the disease. Yet, after going through the

patients' squeeze data and nurses annotations a possible difference between the tools was seen for at least some patients. One some days the ESAS-r form was skipped as indicated by a red circle (refer to the previous Figure 3.4), or nurses annotations such as " [patient] cannot endure daily ESAS-r". However, for several of these days Grasp data has nevertheless been recorded both prior to and after the intended ESAS-r.

Other nurses highlighted the potential of using Grasp at home or between medical check-ups. Patients are often re-admitted to the hospital, and Grasp could be used as an at-home follow-up. Some nurses pointed out that several patients between thirty and sixty years were high functioning and would be able to gain more from Grasp. They would benefit from using the Grasp interface on their phones to follow up on symptoms. N2 expressed that "Grasp I think could have been a very great tool, maybe for the healthier patients..." and that it could be useful for at-home assessments.

6.3.8 Changes takes time: "we do not have time"

All nurses voiced concerns over the staffs hesitancy to use ESAS-r and Grasp. As N4 put it "there is a well-known thing in our ward that everything new is 'no, we are not interested in this! We will not be bothered'... It is a process of getting them interested and getting them to understand what it is". Whilst some nurses applied ESAS-r diligently, most had to be reminded. With ESAS-r "they simply need some time and repetition. Sometimes I feel like I am just nagging..." N4 said. N2 agreed by saying "we struggled with it for a long time, myself included, so there is something about incorporating new things, at least some...". Similar resistance was met when trying to introduce Grasp. They were a little negative at first saying 'we do not have time... yes, but what are we going to do with it?'", N3 said. As Grasp was not mandatory, nurse staff did not prioritize it. N4 tried to slowly introduce it to the others by talking about Grasp and using it herself. Then she introduced others "'now you [nurse] come with me, and then tomorrow you will read [upload and look at data] the Grasp'... and suddenly I started to see that the iPad was on the desk and that they had started to click on it and see... ". Nurses had slowly but on their own initiatives started to interact with the Grasp interface after seeing it in the lunchroom. As mentioned in previous sections, multiple factors and barriers affect the daily operations of clinical environments. Nurses and doctors are under pressure racing against the clock. Consequently, everything new may be perceived as extra work and stress, rather than potential resources. The recommended procedure of ESAS-r does not consider the workload and effects it has on nursing staff. Understandably, it can be hard for them to adhere to guidelines that are not already incorporated. It appears to be a question of resistance towards change rather than specific tools.

Changes takes time

Participating nurses had observed that nurses interest towards ESAS-r had only changed a little or remained the same before and after the trial. N1 said, "we see that they are starting to wake up...but I still do not think the nurses see the efficiency of it [ESAS-r]... when it becomes routine, then we can start to see the effect of it ". This further underpins nurses and patients feedback that the trial had been too short. One nurse said her views on ESAS-r had become a little more negative after seeing how the patients struggled: "that snapshot, I am more negative towards it now than I was before". She

believed nurses initial resistance towards ESAS-r persisted. N4 observed that there had been some changes towards the positive. She mentioned that nurses who had used ESAS-r in the past and simply forgotten about, now were reminded that they had a tool to assist them. N2 who already used ESAS-r on her own had a positive experience with entering the data into the journal system. She described it as useful and motivating, enabling her to see previously entered symptoms.

In comparison, interest in Grasp had increased drastically. By the end of the study, more nurses started to suggest suitable patients and inquired about the tool. Nurses commented how ironic it was that attitudes had changed towards the positive now that the trial was finally over. "We have now reached a point where people start to 'oh yes, that Grasp yes, what was that again? Oh, this was quite interesting", N4 said. One may wonder why the interest towards Grasp increased more than that of ESAS-r. It could be a result of nurses not being forced to apply the tool, or that they realized that it required less work than anticipated. With Grasp patients can log their symptoms on their own, and nurses can view the data whenever they have the time. Another nurse reckoned "big changes in attitude. At first no one joined...". She emphasized the importance of innovation and changes within cancer care and added that some nurses still refused to partake saying "they should get another job... it is something they say in interviews here that if you are going to work with us you have to take part in a change...". Another perspective was brought by a nurse who argued that the constant need to adapt to new things generally made nurses and doctors more reluctant "because it comes constantly, so many things all the time...". N4 said that nurses like to get an overview of their patients and if they had just given Grasp a chance, they "would have understood that when you get Grasp you gain an even better overview".

The importance of follow-ups

Irrespective of the tool nurses pointed out that symptom assessment must lead to something. "There is a reason why we map them [patients]...we do it to gain an overview and to see how much and what we can do..." N4 said. N2 explained that if nothing is done, then it would do more harm than good to the patient. It was emphasized that the doctors had to do their part: "but if the doctor does not follow up then we, then it does not work... ". Doctors engagement is imperative for nurses to see the implications and value of their work, and for patients to feel heard and taken care of. One of the nurses also implied that they needed to make sure that the patients see the relationship between reporting their symptoms and receiving treatment.

Grasp as it is today having to be manually synchronized for data to appear on the interface. Nurses commented that Grasp is a "quiet tool" and they wished that they could be notified on their phones or iPad if the patients engaged vigorously. "A patient sits in their room alone and squeezes the ball...but no measures are taken because we do not know about it,"N2 said. N3 remembered a patient saying "no, yes, I want ... I need analgesic, but now ...I need to remember to squeeze ...". She had explained that the patients should not worry and would receive analgesic regardless of squeezing. Automatic data transfer and a notification would have solved the issue. This also sheds light on some of the ethical concerns mentioned previously.

Nurses highlighted the importance of top-down implementation of change. While the Heads of the Section would need to promote new tools actively and insistently

for it to become a part of everyday routine, they also relied on doctors' engagement. Doctors at the ward were unable to partake in the trial due to tight schedules. They were nonetheless present when Grasp was synchronized during the doctors visit. One of the nurses said, "it is also a bit like on the management level as they [doctors] have to be given time...". Doctors were happy about the increased use of ESAS-r, but as a nurse remarked they got "the answers served". "There was a doctor who said that the nurses had become so good at doing ESAS-r and that it was so nice..." N1 recalled. Doctors who had the time to briefly hear about Grasp expressed interest, once again indicating that it is a question of resources and work limitations. N4 felt like they never took the time saying, "they have actually been absent...we [nurses] are trying to bring the iPad and show them at the doctor's round but it gets a little bit like 'no I do not know what I will do with that'...". One comment from the questionnaire mentioned that nurses and patients would have benefited more from Grasp if the doctors partook. The chief physician was "clear that this was great, he believed it was nice" but he just did not have the time N1 explained. She said this was a shame and "if he just cared to look ... at the visualizations he would have seen ... with a quick glance how the patient feels... And then I think he actually would save time...".

Nurses needs and suggestions

For Grasp to further develop and fit into a clinical setting some additional features were desired. N1 said it most importantly should communicate with already existing systems like DIPS, not become an additional system. If data were all in one place it would make it easier for nurses and doctors to go through it together. "That I think is essential...there is little communication between our systems today... I am a bit positive about using Grasp further, but the system must talk to our system...". Another nurse voiced something similar in that she wished that all patient data could be viewed together. That way nurses could read Grasp data and also what measures had been taken to alleviate the symptoms. Related to the importance of following-up self-reports several nurses mentioned that being notified of patient activity would be useful. This requires automatic data transfer. "The dream...that would be to get that pling on the mobile..." N3 said. Although it would require more work for the nurses to attend to possibly several notifications, they argued that the patient would be "not just dependent on nursing staff to come in and ask how you are doing. One can actually express their needs beyond that. And get the help you need outside of the visits... ". One last remark made by N2 was that although Grasp has good battery capacity, patients were worried it would not last through the night as there was no way for them to check the battery level. This is related to the users' need for feedback so that they can be sure that data is recorded.

6.4 Research questions and summary

Through patients' and nurses' questionnaires and interviews, rich data have been gathered on their experience of ESAS-r and Grasp in a clinical environment. This section starts by addressing how data provides insights to the three sub-questions, before looking at the overarching RQ2: *How do palliative cancer patients and nurses perceive Grasp as a tool for the logging, assessment, and communication of pain and symptoms?*.

2A: What is the current practice of symptom assessment at the cancer ward?

It was revealed before the trial, and confirmed by the interviews, that the recommended procedure of applying ESAS-r with patients was generally not done in practice. Nurses who did apply ESAS-r regularly, did not consistently enter the results in the journal system. It was made clear that symptom assessment always took place and was not neglected. Nurses who did not apply ESAS-r would rather converse with patients, and they use their clinical views and experience to assess them. This led to less systematic collection and documentation of symptoms, and some nurses were worried that more ambiguous symptoms like anxiety could go unnoticed.

2B: What are the needs and barriers, nurses and patients face in symptom assessment?

Multiple and complex barriers, related to nurses and patients, were identified. Reasons why ESAS-r had not already been included in the routine include: lack of time, increased workload, short patient hospitalization, patients finding it difficult to use, nurses lack of knowledge about it, and nurses who did not see its value. It is to some extent an organizational problem with a lack of engagement on the management side. Similar issues were seen when trying to incorporate ESAS-r and Grasp. Some challenges are also directly related to cancer and palliative patients, including their clinical pictures, demographics, and their physical and mental conditions. Patients may under-report their symptoms, and they often require nurses' assistance when filling out ESAS-r. Conversation and discussion with patients help them feel seen, but it also implies that the nurses have the time to do so frequently. Patients struggle using numeric values, and they require low-burden, in-situ methods that can help them communicate their symptoms, even when nurses are not present.

Busy clinical environments put pressure on nursing staff and doctors, and it makes the introduction of new tools challenging. It often becomes a question of priorities and extra work, rather than what benefits one may gain. Nurses need symptom assessment tools that are "as easy as possible to use, and then require as little as possible from the employees, and that you can see that it is time-saving ...", but focusing on the introductory phase and implementation of said tools is just as important for clinical staff to be able to see its' value. The management should push for change that can benefit both patients and staff, but time is needed so that new tools can slowly become a part of everyday routine.

2C: What are the challenges and opportunities of Grasp as experienced by patients and nurses?

Patients and nurses shared that Grasp was easy to learn and use, and that it painted a more holistic image of the patients' disease, at least for the symptom in question. It lets patients log symptoms through squeezing, without them having to think about numbers. Nurses reported that Grasp data could encourage more in-depth exploration and communication of symptoms, and it also became "proof" that the symptom had occurred. Yet, they experienced that some of the patients were too far in the disease trajectory to benefit from it. For example, a few experienced constant pain or were too weak to squeeze Grasp. Others would forget to use it, or struggle to squeeze when

experiencing severe symptoms. Grasp was also found most suitable for one symptom only, but patients often experience several at a time. This did not seem to be an issue of special concern as the interface also provides the entering of additional ESAS-r data. One particular concern was that synchronization had to be performed by the nurses and they would therefore not be notified when Grasp was squeezed during the night.

Nurses saw the potential of using Grasp with healthier patients (or introducing it in earlier stages of disease), for symptoms that are difficult to express like anxiety, and for at-home follow-up.

RQ2: How do palliative cancer patients and nurses perceive Grasp as a tool for the logging, assessment, and communication of pain and symptoms?

Overall, patients and nurses are generally positive about Grasp and its potential. The majority of patients and nurses were satisfied with Grasp as a tool, and acknowledged that it is still under development. There are no significant differences between patients' assessment of ESAS-r compared to that of Grasp.

Logging of symptoms: Nurses and patients found Grasp easy to use and apply. Patients can use Grasp as much as they like, and they do not need to consider numeric values, relieving them of some burden. Collecting self-reports thus requires less from nurses than administering frequent ESAS-r. This somewhat solves the issue of infrequent assessment due to time constraints. On the other hand, Grasp requires nurses to come and synchronize it to be able to see the data. Retrospective data is valuable to reveal changes in symptoms and to form a larger picture of fluctuations. However, how frequently it is assessed and obtained relies on the nurses. Patients also found it difficult to use Grasp when experiencing severe symptoms, and they would sometimes forget it altogether. Some participants were too weak to produce data.

Assessing and communication of symptoms: Patients generally experience Grasp to be at least somewhat helpful in gaining an overview of their symptoms, communicating them to their nurse/doctor, and being confident in the treatment they receive. No one answered that it had helped only to a *very small degree*, and 38% said that it had helped communication of symptoms to a high or very high degree. Nurses answered that Grasp had helped gain a better overview of patients' specific symptoms to a high degree, and of their overall disease to at least some degree. The visualizations were easy to understand for both nurses and patients', and they contributed to forming a wider image of the patients' symptoms than just using ESAS-r. Some nurses reported that visualizations enabled easier communication with the patients. When it comes to clinical decision-making and applying the correct treatment nurses were mixed. One believed Grasp had made it much easier, one said it had helped to some degree, and another experienced no particular effect. Whether this again comes down to the engagement of doctors or the lack of notifications of patients' squeezing is hard to say.

6.4.1 Food for thought

There are undoubtedly benefits of numeric and other objective scales for pain and symptom assessment. For example the NRS provides easily comparable scores, is generally quick to assess, and has a reportedly low respondent burden, given that the user can relate to the scales (*Hawker et al.*, 2011; *Karcioglu et al.*, 2018). New tools for

pain and symptom assessment strive to adhere to expectations of accuracy and precision of what is measured. This is a requirement in many use cases. For instance, when assessing how painful a specific procedure is. In that sense, Grasp, as it was used in the clinical trial, is arguably less accurate than a number. Consider the difference between a small circle vs. a small number to represent pain during catheter insertion. In this scenario you only need a snapshot of the patient's pain. A single number may therefore suffice, and provide a more clear-cut idea of the pain, that can be easily compared to other patients. That being said, one should ask what words like accurate and precise truly mean in the context of transforming subjective experiences. The VRS have less response categories than the NRS, and may therefore be considered somewhat less precise (*Karcioglu et al.*, 2018). However, can one compare the number three to the descriptor *mild*? Do they provide the same information? Individual's living with chronic conditions benefit from repeated measures that can help them see changes and trends in their overall well-being, and take an active part in their own care (*Price et al.*, 2018). They might not require the same "numeric accuracy" when logging their experiences. Here, the need for a wider image of the symptoms is more important than a single value, and the tools used must fit into the user's lives by being inconspicuous, and low-burden (*Adams et al.*, 2017; *Morren et al.*, 2009).

From our clinical trial it was seen that some patients' struggle to use numbered scales and require assistance from nurses. Nurses' presence may inhibit patients in their reporting, and their need for help implies a higher respondent burden (*Francke and Theeuwen*, 1994). Furthermore, symptoms like pain are highly subjective and not necessarily transferable to objective measures in the first place. The literature strongly suggests that different individuals and contexts have disparate requirements, preferences and needs (*Hjermstad et al.*, 2012). There seems to be no one-size-fits-all, but maybe that is a product of the nature of pain itself.

Nurses who did not use ESAS-r before the trial still performed symptom assessments by asking the patients directly whether they experienced any pain, where the pain was located, and so on. Within palliative care, it is often a question of whether symptoms are present or not, if the patients need palliation or not, and if measures applied have worked or not. In the trial, the focal point was to log the occurrence and intensity of pain by squeezing Grasp longer/harder. Patients were not presented with the details that were explored in the pilot study. They were simply told to squeeze when experiencing pain. This allowed them to log their experiences more intuitively, without confining them to a set scale with clear boundaries. Although we were not to explore the affective aspects of Grasp in detail, other studies have reported that squeezing may even externalize and ease pain perceptions. Thus, Grasp could potentially provide support other than the actual logging of data. Nurses did not share any desires that visualizations should have been different or more "accurate". Grasp provided them with insights into the patients' symptoms and fluctuations throughout the day and night. It can be the case that the simultaneous use of ESAS-r overshadowed some of the potential pitfalls of Grasp. It might also simply be the case that these tools cater to different, and sometimes overlapping needs, and therefore complement one another. One is not implying that numeric assessment should be completely discarded, ESAS-r is the recommended tool after all, but to encourage open discussion around alternative ways of pain and symptom logging.

6.4.2 Limitations

The study has several limitations that should be addressed. As for sampling, the selective and small number of patients impairs statistical power and limits generalizability to other populations. A couple of patients were included in Phase 1. were hematological. Despite experiencing similar symptoms as the palliative cancer patients, they are inherently different. Some of the participating patients in both phases were also severely ill, and a few passed away. Although the ones who completed the phases were deemed clear-headed, one may question whether they were able to fully comprehend, utilize, and assess the tools.

Another limitation is the short duration of the study, both on the individual level of short hospitalizations, and in general terms. We did not consider the slow adoption of new tools, nor could we anticipate the unusual number of deaths in March, limiting patient recruitment. This affects the evaluation of both tools. It may be that deeper insight and clearer effects would have been revealed, if time had allowed the tools to become a natural part of the ward. ESAS-r was still newly adapted when Grasp was introduced. This may have led to extra stress and negative perceptions. The patients in Phase 2. only assessed Grasp, but as ESAS-r was applied during their stay as well, it may have influenced their answers. The novelty of Grasp itself can possibly have amplified participants' enthusiasm and positive feedback. It is also worth mentioning that all patients used Grasp to log pain, and it is, thus, uncertain whether the responses would have been similar if they had used it for nausea or lack of appetite.

Nurses were the ones to explain and administer the tools and questionnaires. People are naturally different from each other, and the mixing of administrations can cause discrepancies in how information is conveyed. Patients may therefore have different interpretations and understanding of the tools. It was revealed that one nurse did not show the patients the Grasp visualizations, which may have affected both her and the patients opinions on Grasp.

Both studies presented in this thesis were conducted in Norwegian with a Norwegian speaking population. The data collected has been translated, which may impair some of the semantic nuances conveyed. One should also recognize the limitations of the questionnaires that should have included a "no degree " option.

6.4.3 Summary

Several barriers to clinical symptom assessment were seen through the clinical trial at the cancer ward. Although recommended procedures exist they do not always align with common practice due to the limitations of busy clinical environments and factors related to cancer and palliative patient groups. This made the implementation and incorporation of Grasp somewhat difficult. Patients were also limited in their assessments due to the short hospitalization and in some cases inadequate time to evaluate the tools. Nevertheless, patients and nurses described Grasp as easy to use and they were generally satisfied with it as a tool for symptom logging and assessment. Nurses highlighted the benefits and shortcomings of ESAS-r and Grasp and argued that the latter helped paint a large picture of patients' diseases and had a lower patient burden. Yet, the patients involved may have benefited more from Grasp if they were introduced to the tool in earlier stages of the disease. Ethical issues concerning patients' welfare

and their desire to contribute to research were discussed. Findings related to barriers to symptom assessments, patients' and nurses' needs, and pros and cons of ESAS-r are consistent with existing literature. Research on tangible tools using squeeze pressure to log pain exists, but they have mainly been applied as high functioning prototypes in smaller-scaled settings without an accompanying full-functioning, visual interface. In this regard, the clinical trial has provided useful insights into the limitations and requirements that follow real-life applications of the tools. Not to mention,

Chapter 7

Conclusion and Future Work

7.1 Summary and conclusion

This thesis aimed to explore the use of a tangible tool, Grasp, and squeezing as an input method to log symptom experiences, especially pain. The overall findings suggest that there is potential in this approach, and that Grasp to some extent supports the logging, assessment, and communication of patients' pain experiences in a clinical environment.

An initial literature review revealed an abundance of existing tools for individuals' self-reporting of pain and symptoms. It also disclosed that despite research and development of new tools, challenges and barriers persist both related to the tools themselves, the setting in which they are applied, and to the requirements of different user groups and individual preferences. While traditional scales, like the Numeric Rating Scale, are reportedly easy to use and administer, cheap, and accessible, they are unidimensional and aim to map subjective experiences to objective values. These scales only capture a snapshot of the users' experience, and they are prone to biases when applied retrospectively. With the emergence of mHealth and the increase of ICT technologies within healthcare, new ways to capture and log one's health have become available. The pervasiveness of smartphones enables Ecological Momentary Assessment of users' pain/symptoms wherever they are, whenever. Yet, there is a gap between the publicly available apps and the ones that have been investigated in research studies. The latest trend of tangible tools for pain logging aims to offer unique ways of expressing innate experiences through natural interaction. Existing work has focused on the accuracy and validity of using squeeze pressure as an input method. Results have been promising, but the tools remain high-functioning prototypes that have not been tested in clinical settings over time. Nor are they equipped with a complete interface for data visualizations.

Through a mixed-methods research approach, two broad research questions have been investigated: RQ1: *How can tangible interaction through Grasp support the logging of experiences?*, and RQ2: *How do palliative cancer patients and nurses experience Grasp as a tool for the logging, assessment, and communication of pain and symptoms compared to ESAS-r?* From the pilot study, it was found that users are able to use squeezed duration as an input method, even when the margins are small. Grasp was generally well-received, and the majority of participants thought it had potential as an alternative way of recording everyday experiences. The mapping of squeezes to visualizations was perceived as meaningful, logical, and intuitive. Participants con-

sidered the visualizations as important to provide later reflection, and they supplied feedback on the participants' interactions. The simplistic idea of Grasp, with its somewhat ambiguous visualizations allowed for a variety of different use cases and contexts to be discussed. Participants also shared ideas relating to affecting interaction in terms of externalizing and distracting from experiences, and to later reflect upon them.

Support for tangible interaction and Grasp to log experiences was further seen in practice during the clinical trial. Patients and nurses were generally positive about Grasp and its potential. It was considered easy to use, and the majority were satisfied with Grasp as a tool. It helped nurses form a larger picture of patients' symptoms and their fluctuations, as opposed to just using ESAS-r. Some nurses reported that visualizations enabled easier communication with the patients. For patients that faced difficulties in picking a number, Grasp provided an alternative way of expressing and logging their experiences. However, some patients struggled to use Grasp when in severe pain, and they had to be reminded to squeeze the tool. Grasp is also a "quiet tool" and future studies on the needs of individual patient groups and caretakers are needed to bring development further.

While there are several limitations to both of the studies, the research has contributed with additional insights into the potential of tangible tools and squeezeing as an input method to log and assess pain and symptom experiences.

7.1.1 Research contribution

The main research contribution of this thesis is are:

1. The exploration and examination of squeeze duration as an input method. The pilot study revealed that there is potential in further studying interaction through squeezing using other parameters than just squeeze strength.

2. Real-life application and investigation of Grasp in a clinical environment over time. The trial uncovered several barriers to symptom assessment in clinical palliative care consistent with the literature. It especially highlights that change takes time, and perceived disinterest in new tools from clinical staff may be a product of environmental factors, rather than the tools themselves.

3. Patients' opinions of Grasp compared to the recommended symptom assessment form, ESAS-r. No significant differences were seen in participants' responses indicating that the application of Grasp in combination with ESAS-r performed at least equally well compared to ESAS-r alone.

4. Insights from participants, patients, and nurses on Grasp, and how it can be used to log experiences and symptoms. Grasp was deemed easy to use and learn and visualizations were found to support reflection and communication. Grasp addresses some of the existing barriers to pain and symptom logging including the issues of unidimensional and numeric scales, and repeated sampling of patients' symptoms in busy clinical environments.

7.1.2 Future work

As seen from the study, there is potential in using tangible tools and squeezing as an input method to log patients' symptoms, at least pain, in clinical environments and with palliative patients. Due to the small number of patients, some areas were left unexplored. Additional research is needed to examine the clinical implications of Grasp, including whether it can support clinical decision making, or promote patients' agency and control over their symptom management. Implementing Grasp in the cancer ward was a slow process, and the patient group made recruitment difficult. Succeeding studies should consider these limitations. Slowly integrating Grasp over time, before letting the nurses and patients use it for extended periods, will likely result in additional insights. One should also investigate the effects of introducing symptom logging tools at earlier stages in the disease trajectory.

Other patient groups might benefit from Grasp, and future research should look into how the tool can be used as an at-home tool for symptom assessment, in-between clinical check-ups. Not to mention, whether it supports the self-management of individuals living with different chronic conditions. Research on tools for self-regulation and management within mental health, as well as insights from nurses, suggests that individuals suffering from depression or anxiety could potentially avail of a tool like Grasp. Early research on Grasp puts it into a therapeutic context, and this would be interesting to look further into. Participants in the pilot study brought attention to the potential of using Grasp as a distraction or relief from negative experiences. More in-depth explorations of the affective aspects is needed.

Lastly, the clinical trial did not focus on the accuracy of Grasp. Future research could further examine how individuals' experiences can be mapped through squeeze duration and/or strength. Grasp is undergoing developments on the software front, which will enable squeeze pressure as an input method.

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Appendix A: Pilot Study

Table 7.1: Norwegian pilot study protocol and interview guide.

Fokus:	Utdypende:	Kommentarer:
Innledende	1. Ønske velkommen. 2. Infomere om hva som skal skje. 3. Informere om at kun kjønn og alder blir samlet. 4. Muntlig samtykke.	Intervjudelen skjer hovedsaklig etter testene, men ha en åpen dialog.
Introdusere Grasp	* Hvor godt vil du si at du behersker teknologi og hvor komfortabel er du med bruk av ny teknologi? 1. Gi deltaker en Grasp som de kan få kjenne og ta på. 2. Be dem klemme litt på den og kjenne på materialet. * Hvordan kjennes den?	Gi dem Graspen som ikke er knyttet til software.
Introdusere nettsiden	1. Vis deltaker nettsiden uten noe klemmedata. 2. La deltaker navigere rundt selv og stille spørsmål. 3. Instruerer om lengde på klem, poengscore og demonstrer hvordan man holder Grasp-en. 4. La deltaker klemme 1 gang på Grasp som er koblet opp. 5.Last opp data og se på sammen.	
Think-Aloud	1. Be deltaker utføre en rekke think-aloud oppgaver på det eksisterende datasettet alle klem: 1. Når ble første klem registrert? (15.11.21) 2. Kan du finne alle data for november 2021? 3. Kan du gå til overview summary for november. Hvor mange observasjoner er det totalt? (10) 4. Kan du finne 16. november? 5. Hvor mange observasjoner finner du på 16. november? (2) 6. Hvilken tall (score) har disse fått? (2, 10) 7. Kan du zoome inn på dem. Hvilke kateogorier hører de til? (Hard, low) 8. Jeg vil du skal se på 15.november. Hva betyr de rosa sirklene? (lack of appetite) 9. I summary kan du set at det er en rød sirkel. Hva betyr de? (negative lack of appetite, tiredness). 10.Kan du finne tiredness i day by day?	

Oppvarmingstest	1. Vi kjører oppvarmingstest: 1 s , 2 s, 3 s, 4 s. 2. Ser på data. 3. Deretter: 3 korte, 3 medium og 3 lange. Ser på data sammen. Evt gjøre test på nytt om nødvendig.	
Klemtest	Klemtest med randomiserte klem. Se protokoll for oversikt over randomiserte klem-instrukser.	
Intervjudel	1. Forklare at vi skal inn i intervju-delen. 1. Har du gjort deg opp noen tanker om hvilke bruksområder man kunne brukt Grasp til? 2. Nå har du testet hvordan man kan bruke tid til å registere hendelser. Syntes du dette var lett eller vanskelig? 3. Ville du heller ha interagert med den på en annen måte? 1. Hva syntes du om den fysiske uformingen til Grasp? 2. Hvordan var det å klemme på den? 3. Er det noe du skulle ønske var annerledes? 1. Hva syntes du om nettsiden jeg viste deg? 2. Hva syntes du om visualiseringene og dataoversikten? 3. Er det noe du skulle ønske var annerledes?	Styrke, mønster Størrelse, materiale, lett/vanskelig å klemme? Lett/vanskelig å navigere estetisk?
Avslutte	* Har du noe annet du vil føye til eller som du ønsker å snakke om? 1. Takke for deltakelsene. 2. Kan kontakte meg dersom det skulle være noen spørsmål.	

Appendix B: Clinical Trial

Appendix B includes material used in the clinical trial: questionnaires, ESAS-r, consent form and the semi-structured interview guide.

Figure 7.1: Patient quetionnaire: ESAS-r

I noen dager har du jevnlig fylt ut et skjema for symptomkartlegging (ESAS-r). Vi har noen spørsmål om bruken av dette skjemaet.

	Svært høy grad	Høy grad	Noen grad	Liten grad	Svært liten grad	Ikke relevant
I hvilken grad synes du spørreskjemaet (ESAS-r) har hjulpet deg i å få oversikt over plagene dine?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du spørreskjemaet har hjulpet deg i å kommunisere plagene dine til behandler?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du spørreskjemaet har hjulpet deg i å være delaktig i avgjørelser rundt din behandling?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du spørreskjemaet har hjulpet deg i å være trygg på behandlingen du får?	☐	☐	☐	☐	☐	☐
I hvilken grad har bruk av spørreskjemaet ført til økt uro rundt plagene dine?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du spørreskjemaet har hjulpet deg å kommunisere plagene dine til pårørende?	☐	☐	☐	☐	☐	☐

Figure 7.2: Patient questionnaire: Grasp

Du har i noen dager brukt Grasp og et skjema for å kartlegge symptomer (ESAS-r). Vi har noen spørsmål om bruken av Grasp sammen med skjemaet.

	Svært høy grad	Høy grad	Noen grad	Liten grad	Svært liten grad	Ikke relevant
I hvilken grad synes du Grasp har hjulpet deg i å få oversikt over plagene dine?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du Grasp har hjulpet deg i å kommunisere plagene dine til behandler?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du Grasp har hjulpet deg i å være delaktig i avgjørelser rundt din behandling?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du Grasp har hjulpet deg i å være trygg på behandlingen du får?	☐	☐	☐	☐	☐	☐
I hvilken grad har bruk av Grasp ført til økt uro rundt plagene dine?	☐	☐	☐	☐	☐	☐
I hvilken grad synes du Grasp har hjulpet deg å kommunisere plagene dine til pårørende?	☐	☐	☐	☐	☐	☐

De neste spørsmålene kommer vi med noen påstander om bruken av Grasp. Du må angi på skalaen hvorvidt du er enig eller uenig i påstandene.

	Helt enig	Delvis enig	Nøytral	Delvis uenig	Helt uenig	Ikke relevant
Grasp var enkel å bruke	☐	☐	☐	☐	☐	☐
Det var enkelt å forstå dataene som ble presentert i verktøyet	☐	☐	☐	☐	☐	☐
Jeg er tilfreds med Grasp som hjelpemiddel	☐	☐	☐	☐	☐	☐
Det var vanskelig å bruke Grasp når jeg hadde sterke symptomer	☐	☐	☐	☐	☐	☐

De neste spørsmålene er åpne, og du kan selv skrive inn svar eller kommentarer

Hva synes du om å bruke Grasp?

Var det noe som var spesielt bra eller dårlig?

Er det noe du ikke har blitt spurt om, som du ønsker å legge til?

Figure 7.3: Nurse questionnaire: ESAS-r and Grasp

Spørsmål om bruken av Grasp sammenliknet med ESAS-r alene

	Svært høy grad	Høy grad	Noen grad	Liten grad	Svært liten grad	Ikke relevant
I hvilken grad synes du Grasp gav deg en dypere forståelse for pasientens sykdomsbilde, sammenliknet med ESAR-r alene?	☐	☐	☐	☐	☐	☐
I hvilken grad bidrog Grasp til å gi bedre oversikt over pasienten sine spesifikke plager, sammenliknet med ESAS-r alene?	☐	☐	☐	☐	☐	☐
I hvilken grad gjorde Grasp det enklere å iverksette riktig behandling og tiltak, sammenliknet med ESAS-r alene?	☐	☐	☐	☐	☐	☐
I hvilken grad bidrog Graps til bedre kommunikasjon med pasientene dine, sammenliknet med ESAR-r alene?	☐	☐	☐	☐	☐	☐

Påstander om Grasp-løsningen

	Helt enig	Delvis enig	Nøytral	Delvis uenig	Helt uenig	Ikke relevant
Visualiseringen til Grasp var enkel å forstå.	☐	☐	☐	☐	☐	☐
Grasp var enkel å bruke.	☐	☐	☐	☐	☐	☐
Grasp ga meg nyttig informasjon om sykdomsbildet til pasienten.	☐	☐	☐	☐	☐	☐
Jeg er tilfreds med Grasp som verktøy.	☐	☐	☐	☐	☐	☐
Visualiseringen til Grasp la opp til en enklere dialog med pasientene mine.	☐	☐	☐	☐	☐	☐
Det var vanskelig å implementere Grasp i den daglige arbeidsrutinen.	☐	☐	☐	☐	☐	☐
Bruk av Grasp har gjort det lettere å ta kliniske beslutninger ved Grasp og ESAS-r, enn bare ved ESAS-r alene.	☐	☐	☐	☐	☐	☐

De neste spørsmålene er åpne, og du kan selv skrive inn svar eller kommentarer

Hva har vært bra ved bruk av Grasp, hva har evt. vært dårlig?

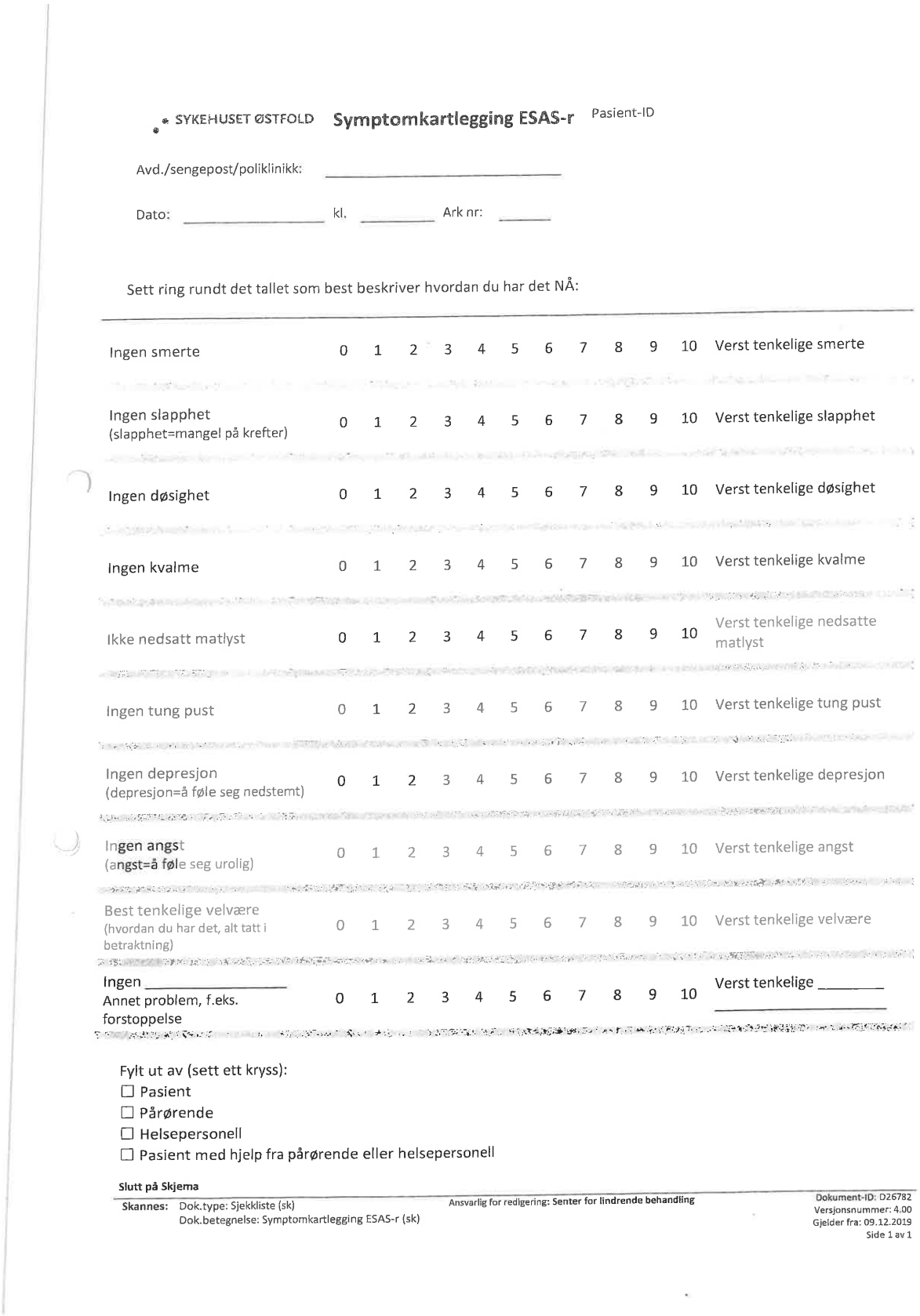
Er det noe du ikke har blitt spurt om, som du ønsker å legge til?

Table 7.2: Norwegian guide for nurses' semi-structured interviews

Fokus:	Utdypende:	Kommentarer, stikkord
Innledende	1. Ønske velkommen 2. Forklare hva vi skal gjøre 3. Starte lydopptak Kan du fortelle litt om deg selv og hvor lenge du har jobbet som sykepleier? Kan du ta meg gjennom en typisk dag på jobb og dine oppgaver? Kan du snakke litt mer om pasientkontakten dere har? * Hvor ofte går dere inn til dem? * Hvordan er kommunikasjonen rundt symptomer og behandling? * Hva med veldig syke pasienter? Hva er de største utfordringene i arbeidshverdagen?	Legg til oppfølging der det passer seg. Tid, prosedyrer, arbeidskraft?
Generelt om studien	Hvordan synes du det har vært å delta i denne studien generelt? Hvordan har dere vurdert pasientenes almenntilstand i forhold til om de kan delta i studien eller ikke?	Spurt dem?
ESAS-r	Hvilken erfaring har du med bruk av ESAS-r fra tidligere? Hvordan bruker dere dette skjemaet til vanlig (før studiet)? Hvilke tanker har du om ESAS-r som et verktøy? Hvordan har det vært å skulle bruke ESAS-r daglig? * Hvordan har det fungert i praksis? Har det vært noen problemer med daglig bruk av ESAS-r? Hvordan har du brukt datene fra ESAS-r? * Symptomer * Sykdomsbilde * Behandling (beslutninger) * Kommunikasjon Hvordan opplever du at pasientene forholder seg til ESAS-r? * Forstår de skjemaet? Snakker dere med pasientene om svarene? Har du gjort deg opp noen nye tanker rundt ESAS-r nå som du har brukt det daglig?	Brukt før? Hvor ofte? Lett/vanskelig? Lett/vanskelig? Kommunikasjon? Reaksjoner Styker/ulemper Endringer?

ESAS-r og Grasp	Hvordan synes du det gikk da dere skulle ta i bruk Grasp? Opplevde dere noen spesielle utfordringer? Hvordan har det vært å innlemme Grasp i arbeidshverdagen? Hvordan synes du det gikk å tolke visualiseringene og dataen fra Grasp? Hva synes du om denne dataen? Hvordan har du brukt dataene fra Grasp? * Symptomer * Sykdomsbilde * Behandling (beslutninger) * Kommunikasjon Hvordan gikk det å introdusere Grasp til pasientene? * Hva var rekasjonene deres? * Hvordan reagerte de i forhold til ESAS-r?	Lett/vanskelig? Opplæring? Nytteverdi
Pasienter	Hvordan har pasientene brukt Grasp? * Hva har de brukt den til? Kan du fortelle litt om hvordan det har vært å bruke Grasp i forhold til ESAS-r alene? Var det noen spesielle utfordringer som oppstod ved bruk av Grasp? Har du gjort deg opp noen tanker om hva so var bra eller dårlig med Grasp? Er det noe du skulle ønske var annerledes?	Forklare dem det. Visualiseringer? Snakke om symptomer? Ansatte/pasienter Teknologi Praktisk bruk
Fremtiden	Hvordan synes du det har vært å delta i denne studien generelt? Kan du se for deg at Grasp er noe du ville brukt igjen i fremtiden om det ble en tilgjengelig løsning? * Hvorfor/hvorfor ikke? * Hvordan ville du har brutk den?	
Oppsummer og avslutte	1. Oppsumer samtalen Er det noe mer du har lyst å tilføye, eller noe vi ikke har snakket om? Takke for deltakelsen	

Figure 7.4: ESAS-r



SYKEHUSET ØSTFOLD **Symptomkartlegging ESAS-r** Pasient-ID

Avd./sengepost/poliklinikk: _____

Dato: _____ kl. _____ Ark nr: _____

Sett ring rundt det tallet som best beskriver hvordan du har det NÅ:

Ingen smerte	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige smerte
Ingen slapphet (slapphet=mangel på krefter)	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige slapphet
Ingen døsighet	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige døsighet
Ingen kvalme	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige kvalme
Ikke nedsatt matlyst	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige nedsatte matlyst
Ingen tung pust	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige tung pust
Ingen depresjon (depresjon=å føle seg nedstemt)	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige depresjon
Ingen angst (angst=å føle seg urolig)	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige angst
Best tenkelige velvære (hvordan du har det, alt tatt i betraktning)	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige velvære
Ingen _____ Annet problem, f.eks. forstoppelse	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige _____ _____

Fylt ut av (sett ett kryss):

☐ Pasient
☐ Pårørende
☐ Helsepersonell
☐ Pasient med hjelp fra pårørende eller helsepersonell

Slutt på Skjema

Skannes: Dok.type: Sjekkliste (sk)
Dok.betegnelse: Symptomkartlegging ESAS-r (sk)

Ansvarlig for redigering: **Senter for lindrende behandling**

Dokument-ID: D26782
Versjonsnummer: 4.00
Gjelder fra: 09.12.2019
Side 1 av 1

Figure 7.5: Consent form nurses

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om forskningsprosjektet ved Kreftavdelingen ved Sykehuset Østfold i samarbeid med UiB og Grasp AS. Jeg samtykker til:

- å delta i intervju på telefon eller videomøte med ressurser fra Universitet i Bergen
- at intervju kan tas opp
- å delta med svar på spørreskjema
- at mine personopplysninger lagres konfidensielt og i samsvar med personregelverket, og anonymiseres ved prosjektslutt. Tilbakemeldinger og erfaringer med bruk av Grasp vil bli lagret ut over prosjektets sluttdato, men de vil være anonymiserte og ikke inneholde noen persondata.

(Signert av prosjektdeltaker, dato)

Figure 7.6: Consent form patients

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om klinisk studie ved bruk av kartleggingsverktøy ved Kreftavdelingen, Sykehuset Østfold, og har fått anledning til å stille spørsmål til prosjektansvarlig Andreas Stensvold. Jeg samtykker til:

- å delta i samtale om bruk av verktøyet
- å delta med svar på spørreskjema
- at mine personopplysninger lagres konfidensielt og i samsvar med personregelverket, og anonymiseres ved prosjektslutt. Tilbakemeldinger og erfaringer med bruk av verktøyet vil bli lagret ut over prosjektets sluttdato, men de vil være anonymiserte og ikke inneholde noen persondata.

(Signert av prosjektdeltaker, dato)