

A TANGIBLE UNDERSTANDING OF CHRONIC PAIN

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ABSTRACT

Pain is essential as a warning system for the human body. For some people, however, pain develops into a chronic condition. What makes it particularly difficult to care for patients with chronic pain conditions is that pain is an individual, subjective feeling. Traditionally, medical experts recommend that patients express their pain experience on a numeric scale or with standardised terms, but patients find this too simplistic to convey their condition. Also, the challenge that pain is a social issue, affecting patients' work and social life severely, urged us to look for alternative ways in which people might communicate their pain experiences. In this project we set out to use design materials to 'design' better communication means for patients to convey their pain experiences. In the process we realised a need to develop a tangible vocabulary for grasping what pain is really about.

INTRODUCTION

Pain is the body's own warning system cautioning you that something is amiss (Käll, 2012). When you touch a sharp edge, for instance, your body will convey a distress signal for you to remove your hand from the edge that is causing the pain. For some people, however, pain develops into a chronic condition, in which pain becomes a recurrent agony with no obvious link to a peril. The International Association for the Study of Pain defines that "*Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*" (IASP, 2012). Pain is deemed chronic when the pain persists or recurs longer than three to six

months (Treede et al., 2015). We will relate our work to the International Classification of Diseases Category for Chronic Pain, which covers seven categories of clinically relevant disorders within chronic pain: chronic primary pain, chronic cancer pain, chronic posttraumatic and postsurgical pain, chronic neuropathic pain, chronic headache and orofacial pain, chronic visceral pain, and chronic musculoskeletal pain (Treede et al., 2015).

What makes it particularly difficult to care for patients with chronic pain conditions is that pain is an individual, subjective feeling. When a patient is in pain it can be hard as a family member or colleague to relate to a number or a verb as professional pain scales suggest. Instead, we explore how tangible material may help expressing and sharing experiences of pain. The main objective of this paper is to study how chronic pain can be expressed and understood with the help of tangible tools and to contribute to understanding of how people experience chronic pain in their everyday life.

RESEARCH METHODS

This project was an exploratory design research effort. We relied on the Participatory Design approach to create new ways of communicating pain. The participants were recruited through a patient group on Facebook for young people aged 12-35 with rheumatic and muscular diseases (FNUG, 2019). All participants are women between age 27 and 33 (Table 1). While the participants all have different diagnoses, their pain has turned chronic, classified within three of the seven chronic pain categories (Treede et al., 2015); chronic musculoskeletal pain (Gina, Janet and Tara), chronic primary pain (Tara, Mary, and Cara) and chronic posttraumatic pain (Sara).

We developed a set of Design Probes (Gaver et al., 1999; Mattelmäki, 2005), which we delivered to the participants to encourage them to self-report their emotions, dreams and daily experiences. Probing has advantages when engaging vulnerable people, like chronic pain patients. Because of their diseases' uncontrollability, it can be hard for them to participate in planned sessions in person because they never know when their disease will 'break out'. Besides, it might take too much of their energy to participate in, for instance, a focus group interview, and with probes, they can take their time at home to fill it out.



Figure 1 - Examples of returned probe kits

In line with Mattelmäki (2008) we followed up with a sharing session for us to understand what the participants had produced – albeit on Skype due to their particular conditions.

We designed the probe kit with a richness of physical materials to prompt the participants to explore with the materials what their pain actually feels like, and what it does to them, Figure 1. As the first author herself understands chronic pain, the materials were selected in respectful care for the participants. Rather than bank on written words or visuals, we take inspiration from Knutz et al. (2018) to see ‘materiality as a process of doing and negotiating meaning’. Out of the nine assignments in the probe kit these four were most successful in making pain tangible:

‘*Frame Your Pain*’ asked the participants to take a picture from the real world and frame their pain in it.

‘*Shape Your Pain*’ asked for a shape to explain what it means to be in the participants’ body, when in pain.

‘*Pain Materiality*’ aimed to explore how the participants would materialise their pain.

‘*The Voodoo Doll*’ allowed the participants to manipulate a doll in any way they felt like when in pain.




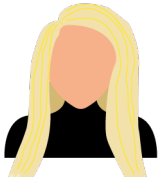

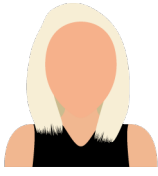
To further co-explore the experiences of pain we invited the participants to a workshop with three steps: (1) unpacking the probe, (2) mapping social relations, and (3) co-creating a ‘pain communicator’, Figure 2.

Based on an analysis of the probes materials and workshop results, we set out to design ‘tangible pain communicators’ for the participants and to get their feedback on the results.



Figure 2 – Gina and Mary working on their ‘pain communicator’ during the workshop.

Table 1: Patients in the project (anonymised).

Participant	Chronic pain conditions
	Janet (33) was diagnosed with Juvenile Idiopathic Arthritis at age 6 and is now diagnosed with Rheumatoid Arthritis. Side effects of her diagnoses have led to chronic pain in the last 10 years. She works part time in a flex job as an administrative worker. She seldomly communicates her pain to other people, even though she is in pain every day.
	Cara (28) was diagnosed with Fibromyalgia and has been suffering from chronic pain since she was a girl. She is currently unemployed after finishing her master’s degree. She occasionally talks to her family about her pain; however, she was raised not talk about it to other people.
	Gina (28) was diagnosed with Juvenile Idiopathic Arthritis at age 8. She works full time as an engineer. She primarily talks to her mother about her pain, as she does not want to burden others. In addition, growing up as the ‘sick’ girl, she does not want to be perceived in that way in her adult life.
	Sara (27) suffers from chronic pain after being in a car crash, where she broke her wrist and back. She works 2-3 hours per day and hopes to be awarded a flex job soon. She keeps her pain to herself, as she does not want to hurt others with her suffering.
	Tara (32) was diagnosed with Colitis Ulcerosa ten years ago and was diagnosed with Spondylarthritis in late 2016. She works in a flex job. She shares her ups and downs as a blogger.
	Mary (27) was previously suffering from Juvenile Idiopathic Arthritis, and now has the diagnosis Fibromyalgia. She has been unemployed the last three years due to her pain and is currently undertaking a ‘resource procedure’. She only shares her pain with a few friends.

PAIN IN PHYSICAL FORM

Pain is challenging to express, not just because “*language runs dry*” (Woolf, 1967) but because it is hard for the individual to grasp the experience itself (Scarry, 1985). In health care, pain (both chronic and acute) is mainly communicated through pain scales, of which there are several: the McGill Pain Questionnaire, the Visual Analog Scale, and the Numeric Rating Scale (Hawker et al., 2011). Commonly, the scales ask patients to rate their experience on a scale from 1-10, or through the use of adjectives, such as burning. The challenge for doctors is to understand whether the pain increases, decreases or stagnates over time. This is the rationale behind the scales. However, relating to a number, or an adjective, can be rather difficult for patients. A pain level at ‘7’, for instance, might seem high for a person normally not in pain, but can be an everyday sensation for a chronic pain patient. Therefore, using pain scales to communicate with relatives in everyday life, can be difficult and lead to misunderstandings.

Even if experts agree that pain cannot be seen, touched or heard (Biro, 2010; Käll, 2012), it was convincing to see how all participants managed to express their pain in physical form. We expected that the outcome of the physicalization activities would be somewhat diffuse and abstract, as many patients try to avoid a constant reminder of their pain. But we were surprised by how clear the messages were: Cara’s ‘Shape your pain’ (Figure 3 left), for instance, though fairly abstract, describes a shape, which in the beginning is a round, soft, and fine ball. The jags (symbolising the pain) are ruining it. The ball slowly becomes flatter, loses its shape, but continues to be, despite of the jags. Janet’s example is more literal (Figure 3 right). It shows what it feels like to be in her body with pain. She sees herself in a black void, penetrated by sharp needles.



Figure 3 - Examples of 'Shape Your Pain' - left Cara and right Janet

Pain is difficult to express, because it can be painful even to investigate, as Gina explains with her ‘*Shape Your Pain*’ probe exercise, Figure 4:

“the shape illustrates how my general pain is often this stabbing feeling... and it is hard to get into the core of the pain. Because no matter how you approach the pain, there will be a new stabbing sensation before you get to the core of it – and I’m not even sure you can”.



Figure 4 - Gina’s ‘Shape Your Pain’

Therefore, even in her self-understanding of her pain, Gina often avoids going deeper into how it feels like, as she thinks it is impossible.

Sara chose a rubber band to demonstrate how her pain feels. She pulled back the rubber band and let it go – ending with a loud snapping sound, Figure 5. What she elegantly expresses with the rubber band is not just the feeling of pain itself, it is also the fearful anticipation that it *will* hurt, when it snaps, even if you may not know precisely when it kicks in.



Figure 5 - Sara showing how her pain feels as an enormous rubber band snapping back at her

EXPRESSING PAIN

Confronted with the variety of physical expressions of pain that the participants developed, we got curious to see, if it is possible to derive general insights into pain and the tangible vocabulary that the participants develop.

ALTERNATIVE AFFORDANCES

The participants use materiality with great creativity when trying to express their pain. Each material has its qualities. Even when several participants chose the same material, it was often not for the same reasons. For instance, the sandpaper and yellow rubber band was chosen by several participants.

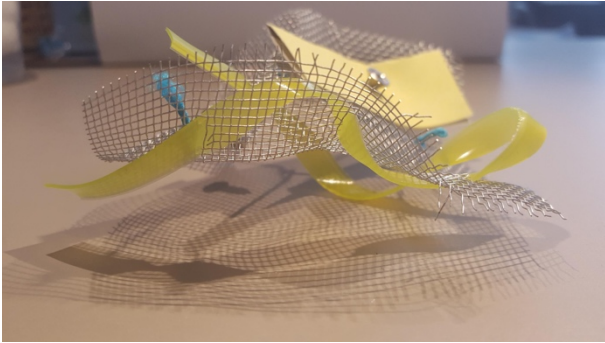


Figure 6 - Gina's 'Materialise your pain' includes yellow rubber band, sandpaper and a metal net

Gina uses the yellow rubber band to show that her pain is inflexible; you can only stretch it to a certain degree, Figure 6. Sara uses it to illustrate that her pain is a little stretchy but can suddenly turn very sharp like the breaking point of the rubber band – when it snaps, it breaks. Similarly, with the sandpaper: Sara uses it to express her pain as something like a numbing feeling, where for Gina it is more a tearing and abrasive stiff feeling.

If we use a wide definition of affordances it can help us explain. Kaptelinin (2012) suggests affordances are both the perceived and actual properties of the thing, those fundamental properties that determine just how the thing could possibly be used. The stipulated actions of how to use the material – sandpaper is made for sanding – are not necessarily the affordances the participants pick up on. The material/artefact can be used for something that was not considered in the initial design of the material. Using sandpaper to describe pain as something numbing reveals an ‘alternative’ affordance. Participants utilize the materials in the probe kit to negotiate different meanings (Knutz et al., 2018). Even between patients with similar diagnoses, the materials aid them to describe and negotiate their pain.

PAIN METAPHORS

Biro (2010) claims that the risk of isolation is high when patients do not have words to express their pain. As pain has no shape or form to describe it, he proposes three strategies of metaphors to describe pain; the Weapon, the Mirror and the X-ray strategy.

The Weapon strategy applies types of weapons to explain one’s pain (Biro, 2010). For example, a patient could say that the pain in her ankle feels like being stabbed by a knife. However, there is a danger in relying on one metaphor only – the metaphor risks losing its integrity. Picture running and having a stabbing pain in the side. When your friend in pain says that her ankle

pain feels like a stabbing knife, you might think “that’s not that bad – it will stop after a while”. In the case of chronic pain - it simply will not disappear, which can be challenging to relate to.

The Mirror strategy attempts to validating one’s pain in others, as to feel recognised one needs responses from others. Projecting metaphors on other people, creations or forms can enable the sufferer to express their pain. Through metaphors one can borrow from the world of form and meaning (Biro, 2010), and thereby connect pain to objects one can objectify pain.

The X-ray strategy suggests that one, metaphorically speaking, dissects the body with x-ray (Biro, 2010). Because it is almost impossible to use any of our senses (see, hear, touch, taste or smell) on the interior of our bodies, it can be difficult to express the sensations our body gives us (Biro, 2010).

Though the different metaphor strategies can provide partial language for the patient in pain, it has limitations. Biro suggests language metaphors as the only way to express pain. This we contest by showing how metaphors can appear also in physical forms. Using materials to turn metaphors tangible opens new possibilities. We have come to distinguish between *physical* and *tangible* metaphors: A physical metaphor can be perceived in relation to the body - for instance, a strike of lightning: you can see it, even though it is not possible to actually touch it. A tangible metaphor is something the body can interact with it – the metaphor is an object. Below we have analysed how the participants use the tangible metaphor of ‘weight’.

THE WEIGHT OF PAIN

The ‘weight’ was a part of the ‘*Pain Materiality*’ set. Several participants chose to use it, albeit somewhat differently. Since a weight is heavy, as a metaphor it relates to the weapon strategy; something heavy can crush you. Cara uses the ‘weight’ as a tangible metaphor, Figure 7 left:

“My pain is as a heaviness, but it also bruises with this stabbing and pinning pain. Therefore, I chose the weight with its heaviness, metal wire which stabs and a soft and warm thread.”

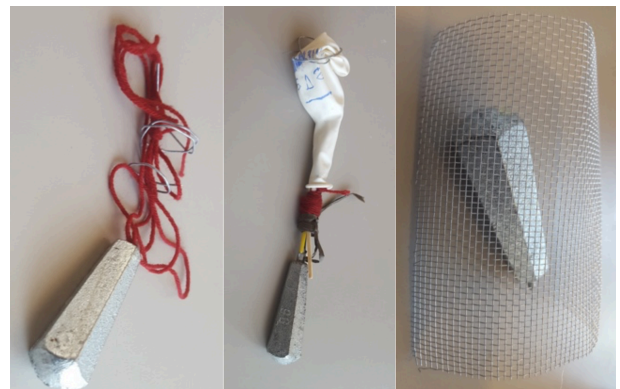


Figure 7 - Examples of the ‘weight’ as tangible metaphors. From the left Cara, Janet and Tara’s materialise your pain.

Janet's 'Pain Materiality' appears quite similar to Cara's – both of them use the weight, red thread and metal wire, Figure 7 mid. But where Cara applies the 'weight' as literal metaphor, Janet says:

"My thoughts behind this quite weird person is that I wanted to try to illustrate, that I sometimes explain my pains as the body feels as lead (heavy, crooked and deformed). The metal wire wrapped around the head is all thought thoughts the pain brings forward."

Here, the properties of the weight are more significant and relate to the weight in comparison to lead. She applies a mirror strategy. Tara describes her pain as a weight being heavy – pulling her down. But for her it means that the pain is trapping her inside of her body, Figure 7 right. She thinks of her pain as a cage she cannot escape, as there is no key to open it and be free of the pain. Aligning with Biro's strategies, her 'cage' works as a mirroring strategy, where you try to objectify the pain. The weight, on the other hand, like Cara's, remains the weapon strategy.

The physical and tangible metaphors seem to work well for the participants is because of how they can objectify (or reify) the pain in a physical form. They want other people to understand what the pain does to them, not inflict it on them. Articulating that it hurts, and that you feel as if you are being pulled down, adding the weight can give more 'power' to the statement, as the receiver gets a reference point.

INTERCORPOREALITY

Käll (2012) challenges Scarry's postulate of 'unsharability' with the concept of 'Intercorporeality', proposed originally by Merleau-Ponty. *"Intercorporeality focuses on the relationship between one's own body and that of the other in order to illuminate intersubjectivity and social understanding in an alternative manner"* (Tanaka, 2017). Käll notes that when you see someone bruised, you can look at the marks on their skin as presenting an experience. Though you can never have the same experience, you will be able to compare it to your own experiences (Käll, 2012). Intercorporeality provides an understanding of the lived body. To refer to something invisible like chronic pain, however, is more difficult. Only knowing patients for an extended period of time will help others perceive their subtle signals, like facial expressions. Chronic pain is inaccessible, it is a bodily event, which we cannot see or touch (Käll, 2012). Though intercorporeality can permit some reflections of what the pain can feel like, it will not give a complete understanding.

WHERE IT HURTS

The 'Voodoo Doll' turned very popular as a way of explaining pain in the body. Gina described her doll:

"I do think that it is easier to show something, which people can see and feel/touch. This way they can better understand how you are feeling."

While *how* it hurts is important, the Woodo Doll showed that *where* is equally as important. The location of the pain affects the participants in various ways. Figure 8 shows how participants used their 'voodoo dolls' in different ways. Gina chose to cut off the arm of the doll, to emphasise that sometimes she simply wished she could cut off her arm to make her pain go away. But at the same time, it was vital to her, that the arm was still attached. Janet chose to 'tie' up her doll to stress how she feels her pain is affecting her, and that it is hard to keep her head 'high' as the pain is pulling it down. Janet, Tara and Sara 'tied' their Voodoo Doll up in diverse ways, and Sara and Tara used the pegs to illustrate how their pain cause them tensions – respectively in the shoulder and the back. Thus, the dolls provided a convincing means for the participants to exploit intercorporeality in expressing where and how it hurts.



Figure 8 - 'The Voodoo Doll' displayed from front and back. From left: Tara, Cara, Gina, Janet and Sara

SHARING PAIN

Though the participants articulated that they try not to let the pain affect them and their relations too much - it has proven to them that it is not possible to avoid. This correlates to Johannessen's claim that pain is a social thing (Johannessen, 2011). Sara provides an example of how it affects her work with colleagues:

"Imagine someone is giving you an assignment – while it feels as if an enormous elastic band is pulled and snaps at your back. What the colleague just said you forget due to the excruciating pain. What do you then reply when your colleague asks for the assignment."

Similarly, Gina explains how her pain is like a thunderstorm, and it affects her social life, Figure 9:

"... Or imagine you have plans with friends. During the day your pain is as a thunderstorm – rumbling pain, where you never know when lightning will strike, so even though you might have made plans with someone – you could potentially have to cancel them five minutes before. There is a risk of losing friendships if this happens too often. Especially if you (like me) do not tell it is because of pain"



Figure 9 - Gina picked a photo of lightning to illustrate that her pain can feel like a thunderstorm.

Pain - especially when it is chronic - affects much more than just the person in pain. It can influence one's work life, social life and the relations to relatives and friends.

PAIN IS SOCIAL

The experience of pain is always subjectively understood (Robinson & Singh, 2015; Jonsdottir et al., 2016). Different individuals feel their pain in different ways, and their pain can not wholly be confirmed by physicians or others. While pain is an individual feeling, it also becomes a social issue because people have relatives and friends – *“pain can be understood as a social relationship; that pain emerges in the relation...”* (Johannesen, 2011). When a person is experiencing pain, it will affect the relationships, as one cannot help expressing the pain.

Williams and Craig argue that a crucial aspect of pain is missing in the IASP definition – the sociality of pain (Williams & Craig, 2016). Because people are inherently social, this needs to be taken into consideration when defining pain. In agreement with Johannesen they revised the definition: *“Pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components”* (Williams & Craig, 2016)

Therefore, nurturing relationships while being in pain can be hard, as relatives might not understand why you behave in a certain way. *“Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language”* (Scarry, 1985).

OTHERS DON'T NEED TO KNOW

Because of this ‘resistance to language’, not all patients communicate about their pain experiences. Some of the participants agree that they tend to isolate themselves, when in pain. Janet: *“Communicating my pain is something I seldomly do, as I grew up being told that it is something you don't talk about, and no-one really wants to hear about your pain”*.



Figure 10 - Gina mainly communicates her pain to her mother. However, in the perfect world she would like to share with all the people closest to her.

From the probe studies we learned that most of the participants were reluctant to share pain – even with relatives. We used wooden figurines (Buur et al., 2018) as conversation starters to learn with whom they would communicate about pain, Figure 10. After participating in the workshop, Mary said:

“Doing what we did today, has made me aware of a new way to express, how it feels to be in pain. I actually believe that it has helped me reflect more on my pain, and I might use it to talk about how I feel.”

Gina gave feedback a few months after the workshop:

“I do not usually say so much about my pain. I can say I'm in pain, but have never described it to so many before, as I have after this process. One has to think about how the pain feels. It can give other people an opportunity to understand how I feel and maybe they can try to help me or divert my thoughts from the pain.”

TANGIBLE BOUNDARY OBJECT

A profound advantage we found with the tangible materials was that it makes it acceptable to negotiate with others, what the pain feels like. Rather than question a patient's words of description, relatives can ask questions about the artefact. The material artifact turns into a boundary object (Star 1989) between the person in pain and relatives or friends. Seen as a tool, it will enable explanation on where and how it hurts, and perhaps what is needed when the person is in pain. For instance, Gina explains to Mary how her pain in the elbow feels, Figure 11:

“It's because it is stiff and inflexible, and at the same time scabrous – that's the sandpaper. Then it has a hard-elastic band, which you cannot pull, and it is twisted around”.

The same material might be seen as two different things by the patient and a family member, for instance. In case of Gina's rubber band expression mentioned earlier (Figure 6), other people may not understand her interpretation, but we can all relate to a rubber band, and hence discuss how it might translate into a pain experience.

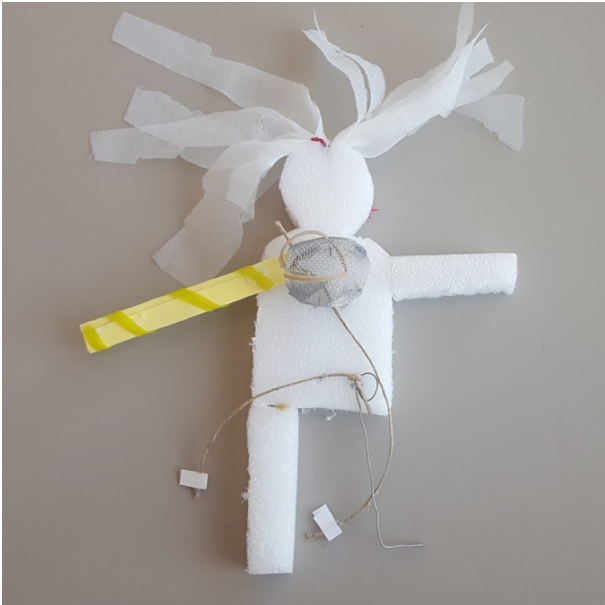


Figure 11 - Gina's pain communicator from the workshop seen from the backside. The metal wire is a cage on her back with snapping (rubber band) pain. The arm is stiff, and the knee is stabbing.

WEARING A MASK

The Faces Pain scale is a self-report measure system used to assess the intensity of children's pain, Figure 12, but is also used for adults with dementia and adults without language (Hicks et al., 2001). The assumption is that the patient can point at a face to communicate to their doctor, relatives or caretakers how the pain makes them feel.



Figure 12 - The Faces Pain Scale (Hicks et al. 2001)

Our participants used faces in the probe kit in slightly different ways. Janet tried to duplicate her usual facial expression, which looks exactly like how she feels, when she is in pain, Figure 13 left. Gina rather chose to put on the happy face that she hopes other people will see, when she is in pain, Figure 13 right. This is how she hides her pain. Mary chose a combination, Figure 13 centre. When challenged on how she would answer her family's or doctors' question of 'how are you?', Gina said that she would always choose a happy face expressing 'I am fine', even though she might be in immense pain. One may wonder, if the Faces Pain Scale would give a useful answer, as Gina would likely check the 'I am not in pain' box, where Janet might hesitate with her 'I am in a lot of pain look' to prevent being perceived as a hypochondriac. This aligns with Jackson's point that sufferers dealing with severe levels of pain might find that the more they talk about their pain, the higher the risk is of being seen as illegitimate (Jackson, 2003).



Figure 13 - The face I make when in pain. Left Janet, centre Mary, right Gina.

The majority of the participants confirmed that they put on a mask - pretending to not be sick or in pain. They do not want to hurt the people around them or have people pity them. Sara shows this in tangible form in her 'Shape Your Pain', Figure 14: The left side of the mask shows how she normally acts: Big eyes, smiles and a big mouth, simply talking around the pain. But the right side shows a twisted eye - how her pain actually makes her feel.



Figure 14 - Sara's 'Shape your Pain'

Mary tells us in words:

"For me, I tend to wear a mask – I am the happy Mary – I feel I have to live up to that image of me, so when I am in pain I put on this mask, instead of risk being misunderstood."

While not showing pain seems 'easier' than being misunderstood, having people pity them, or judged, a main reason for the patients to avoid sharing their pain, is likely because they do not know how to.

Design-wise we thus decided to see if we could devise a 'tangible pain communicator' for each participant, to provide them with a means for expressing their current pain experience to relatives and friends. Through a number of design iterations we developed artifacts we could present to the participants to see if they could become useful.



Figure 15 - The Encyclopaedia of Pain includes: sandpaper (numbing pain), orange thread (nerve pain), nail/metal net (back pain), rubber band (snapping pain), and the clamp (tensions).

TWO TANGIBLE PAIN COMMUNICATORS

In this section we present two examples of tangible pain communicators created for participants based on the probes results and co-creation workshops.

THE ENCYCLOPAEDIA OF PAIN

The tangible pain communicator for Sara is a hollowed-out book, which contains a doll-like figure, with the different types of pains that Sara experiences, Figure 15. It is crucial to Sara that the communicator is something she can hide away easily, and only bring out when she is comfortable and ready to communicate about her pain. In addition to the doll, the book includes bigger versions of the different materials on the doll. Sara argued:

“I don’t want them to feel the pain, but I would like them to understand how it limits me, so by, for instance, tying the wrist up, and wear that for five minutes, should make them understand some of the difficulties I face”.

Besides the material, a sheet of tinfoil is included in the book. The tinfoil gives Sara an expressive way to explain how her pain affects her; rubbing the tinfoil, which gives a shrieking and disturbing sound taking away attention. This seems to be the easiest material to relate to for the people closest to Sara.

THE PAIN DUDE

The tangible pain communicator for Gina is like Sara’s a doll-like shape,

Figure 16. The design aim is for Gina to be able to articulate her four most significant pains. Gina has two ‘stationary’ pains – in her elbow and knee, they will never be better. Therefore, in her ‘Pain Dude’ they cannot be removed. The two-additional pains – in her jaw and back, are not always present, but when they are, they are affecting her a lot. Accordingly, the choice was to make them detachable. In this way she can add them when necessary.



Figure 16 - Gina’s ‘Pain Dude’ includes: Sandpaper/Yellow rubber band (inflexible, tearing and abrasive pain), metal wire in knee (stabbing pain), red and orange felt (burning pain), metal net (stabbing and confining pain).

Gina tried out the Tangible Pain Communicator with her friend Chloe:

Gina: *“It was a fun sensation to face another adult and talk about a figure. But as I just got used to it, it was okay.”*

Chloe: *“It was a fun way to get explained how the pain was located or felt. I think it is good to make things visual for people who have no experience of the same constant pain.”*

Gina: *“I felt that it was easier to say how the pain feels when I had a figure next to me. I could point to it and I had something my friend could look at.”*

Chloe: *“However, it is still hard to feel how it would feel in one joint, but the ability to touch e.g. sandpaper can help me to understand it better. Or for instance feel the tension as the rubber band provides.”*

Gina: *“For example, it made quite good sense to her when I told my elbow to feel like a tight or tense elastic. She tried to pull the elastic and I showed my arm and how I to push it to make it happen.”*

For a first ‘test’ of the pain communicators, we believe there is a potential here.

CONCLUSIONS

In this paper we demonstrate that chronic pain experiences can be transformed into physical forms through probing and co-creation. When challenged with carefully selected materials, the participants showed a remarkable ability to employ tangibles creatively and reflectively to express their pain experiences: How it hurts, and where it hurts. In our analysis we show that theoretical concepts of ‘alternative affordances’, tangible metaphors and intercorporeality can help explain the tangible vocabulary the participants develop. Our participants confirm that pain can be seen as a social phenomenon, and we have developed ways of probing with whom, when and why the participants feel comfortable about sharing their pain experience with others. In the process we have learned substantially

about what chronic pain feels like, and what strategies patients adopt to survive with their pain in daily relationships. We suggest that the utilisation of tangible materials can challenge the current pain scales devised with numbers, words and face icons as a way of sharing pain experience. Tangible materials can both support patients in relating socially, and help relatives and friends - and possibly with medical professions – to extend care. We have devised the concept of “Tangible Pain Communicators” to enable patients to communicate how pain affects them, and what it means to the patient to be in pain. While the number of participants is rather small, our results show great promise for further development of ‘tangible pain communicators’.

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