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# SELF-REFLECTION OF MOVEMENT: EXPLORING THE BODY IN HEALTHCARE EXPERIENCES

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## ABSTRACT

To keep a respectable distance from each other, technology and medicine have each carved people along Cartesian lines. I present two short cases that explore what it would mean to bridge these two perspectives through a simple tool while researching personal experiences of patients as they make sense of their health. The conclusion is that there is a need for research tools to get users to articulate their own movement practices and meanwhile hold a view towards a designerly approach to research.

*Keywords: bodily movements, healthcare experiences, participatory research*

## 1 INTRODUCTION

Medicine and technology have maintained an uneasy alliance. Sullivan contributes the growth of medical technology as a way to perform an autopsy of the living and says, “medicine has pursued the positivist goal of erasing the subject from medical perception” [1]. At first, technology empowered the medical professional and strengthened his/her legitimacy but recently has weakened this role through the expanding role of self-care in chronic disease [2]. A gross simplification of the carving of the person into two halves (Table 1) suggests that technology has traditionally focused on the mind by making interaction as usable and simple as possible (and trying so hard to deny the body’s existence by limiting physical interaction), while medicine through turning away from the social factors of illness (for example, bracketing out the placebo effect) has concentrated mainly on bodily weakness.

Table 1. Carving up the person

	Deny existence of:	Focus on weakness of:
Technology	Body	Mind
Medicine	Mind	Body

The research I draw upon includes working with hemophilia patients [3] and home dialysis patients [2] through design research methods (probes, co-creation) and ethnographic (interviews, observations). Hemophilia is a rare blood-clotting disease where uncontrolled internal bleeding can cause joint aches, hospitalizations and even death. Recommended treatment includes infusion of clotting factor at the first sign of a bleeding. Home dialysis requires the use of a large machine typically hooked up to the patient through the arm for several hours at a time while the blood is cleansed and circulated into the body while at home. In both cases, patients perform healthcare with medical devices.

## 2 LINKING FEELINGS TO ACTION

Rune, a hemophiliac, chooses the template *steps in how it is now* from which to make his collage. He fixates on the list of words and ignores the selection of photographs to tell his experience of a hemophilia bleed:

Maybe to begin with I feel happy. I move around. So I don’t know how this works, so I’ll put it somewhere. What happens then?

Then I get tired and I can sense a bleed somewhere. So.... Sometimes that’s a bit frustrating because occasionally it happens at a time it is inconvenient. Usually it happens while I’m doing some exercise or occasionally in the morning when I’m late for work, then I discover...damn, I have to take the medicine. And even though it only takes five, ten minutes. It’s still annoying when I’m late already.

I find the medicine first. And I prepare the solution. [...] And I inject. I guess then I'm at ease because I know the bleeding isn't going to get any worse. Also the 30 seconds during the injection I can't really do anything else because you've got both hands occupied. So you just have to sit there and relax. So relax. And then I throw away the kit. I dispose of the needle. That is the only part I kept in a special container. And then I...I'm satisfied. I can continue to do whatever I was doing.

Rune explains his experience while creating the collage and find the right words from the possibilities presented. The stickers are the tools to help him think through and articulate his world (Figure 1).

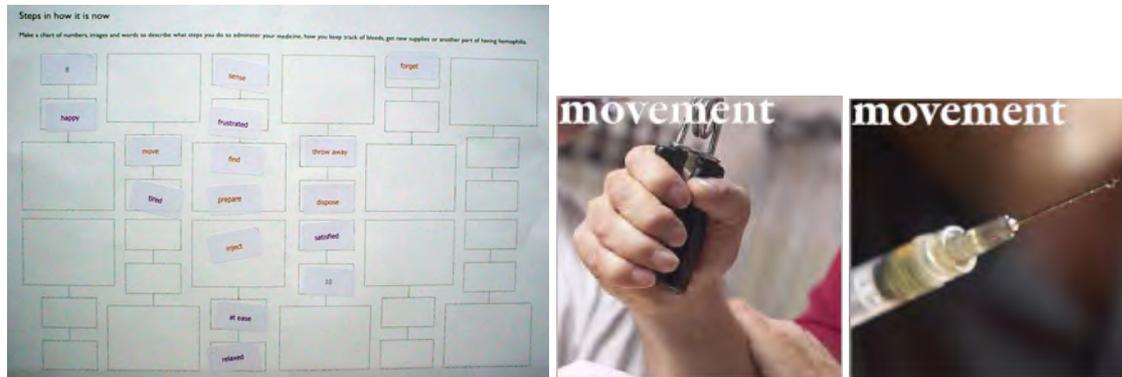


Figure 1: Bridging body and mind using research tools in cooperation with participants.

An interesting aspect is how the collage making allowed him to express his frustration at the time it takes to administer the medication, as this was never mentioned during the interview session. Maybe more importantly, Rune links ways of acting with his body like moving, exercising, and relaxing to his ways of experiencing his world with words like happy, tired, and at ease. He starts with positive experiences of his body, which turns towards frustration as his use of the body necessitates injection of medicine. In this simple narrative, the moving (exercise) acts as a trigger for the disease. Yet during the interview he also points to being active as a way to prevent bleeds and rationalizes that his daily cycling might be the reason his bleeds are less severe than the medical diagnosis should suggest. Overall, the collage tool seems to facilitate a simple one-to-one association of feelings to bodily movements and even challenges aspects learned through only oral interviews.

### 3 REFLECTING ON EXPERIENCES OF THE BODY

In researching the experiences of the body in home dialysis, I asked participants to choose a series of *movement cards*, which featured pictures of people doing things or photos of common tools. Based on this selection, they then were asked to explain how this relates to their experiences of home dialysis. Frederick describes the process of training the fistula, where a vein is removed from the leg and placed in the arm for easier access during dialysis:

This one [Figure 1, middle] because if you have to train a fistula, a way you can do it is to get a little rubber...could be a penguin or something else and you can do it like that. You could actually use the same device to train your fistula in the beginning to make it more developed. Now it is developed, that's why you see it so much, but that's not what it looks like in the beginning.

Another participant describes her experiences with needles and picks the card in Figure 1 (right):

You see when I...before I started dialysis, I had one big fear, that was needles. And a long time before I started dialysis I had to give myself injections. And could stay at least five minutes with a needle in my stomach and say I don't want to, oh, yes you have to do. I did it. That was very small needles, and then when I decided I wanted to do my dialysis at home, I had to look into a very bigger...large needle. It took me some times to say it's alright...I'll try and put it in my own arms. I really was afraid of it. I was sure that it was going to hurt a lot more if I did it myself than when others did it, because they had experience. But one day there was a very nice nurse, a nurse that I trusted very much. And she was very tender and I

said today is the day that I want to try it. And you will have to take over if I can't. Yes, she promised that I will do anything and I just have to do what I wanted. And I got the needle and I sweat a lot, I'll say that. [Laughs]. But when I put in the first needle, I found out that it did less...it hurt more when others do it...because they press your arm together and "roommm" fast...they get the needle in. I do it slower, because of that I'm not going through...[the vein]. I'm not going through it...I'm staying in the vein. I put one needle in and after 5 minutes I put the other one in, and since they...since that day...I've done it myself. I think I got 10 centimeters bigger that day. [laughs] It was really...it was really...out of body experience or what you say body jumping for me or something. I would have sworn I couldn't do that.

The movement cards represent a participatory research tool that involves the people in trying to understand their experiences, rather than leaving those whom the ethnographic material is based upon outside of the interpretation sessions. Ultimately, reflecting and relating it towards design possibilities is appealing in that the user suggests ways of moving the design process forward. Having a skilled practitioner, like the medical device user, articulating the practice in which they operate is powerful as it highlights the interrelations between experiences, body movements and the design of product interactions.

#### **4 CONCLUSION**

While the two cases do not introduce novel methods of approaching research, it does start to address the need to understand the ways in which we develop tools for research and the impacts of the tools on our understanding of bodily experiences. I realize that there is contention between trying to translate body movement into verbal descriptions and metaphors. Jackson [4] says that “body movements often make sense without being intentional in the linguistic sense...Thus an understanding of a body movement does not invariably depend on an elucidation of what the movement ‘stands for’” (p. 329). Understandably, things get lost in the translation, especially since body movements may have meanings within themselves. Jackson leaves an opening for this work however when he says “bodily practices are always open to interpretation; they are not in themselves interpretations of anything” (p. 339). Having these interpretations of body movements can become a powerful influence within the design process as we strive to support embodied skills of healthcare users. Self-reflection may help researchers learn about healthcare practices with limited encounters, while creating a sense of engaging intimacy with users. It attempts to bridge the gap between use practice and design practice.

Concerned with the largely rational approach of medical science, Evans [5] says that to reach the goal of “patient centred medicine,” we need to push beyond the duality of reason and emotion towards genuine dialogue that takes into account a patient’s experience. It is in this spirit of engagement with patients, by understanding them as people, we can hope to design products that reflect their embodied skills.

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