HCI and Intimate Care as an Agenda for Change in Women's Health

Teresa Almeida, Rob Comber, Madeline Balaam

Open Lab

Newcastle upon Tyne, UK

{t.a.almeida, robert.comber, madeline.balaam}@ncl.ac.uk

ABSTRACT

Designing for women's healthcare remains an underexplored area of HCI, particularly outside informational systems for maternal health. Drawing on a case study of a body disruption - urinary incontinence in women - we illustrate the experience of women's health both from the perspective of the patient and the therapist. We show how knowledge, esteem and agency play crucial roles in remedial women's care practices, as well as preventative. In describing these challenges we deliberate on possible futures of women's health that take advantage of the many advances in design and technology from across the spectrum of HCI research. We show how with some care and courage HCI has the potential to transform women's experience within this setting.

Author Keywords

Women's Health; women's experiences; intimate care; observational study; disruption; taboo; feminist HCI; incontinence; pelvic exercise; wellbeing

INTRODUCTION

Women's health tends to be defined as health issues and problems if they only affect women, or if these issues / problems are more prevalent or severe among women. Under this definition women's health will include issues such as menstruation, and menopause, through to cervical cancer, sexually transmitted diseases and pregnancy. Women's health directly impacts upon maternal mortality, cervical and breast cancer mortalities, sexually transmitted diseases, unwanted pregnancies through to sexual violence and female genital mutilation [63]. Delivering good quality healthcare to women is rife with problems. Body disruptions, control, and flux are generally associated with feminist theory [31,58]. In [55] Rossmann argues that the female body has historically been a subject of taboo, limiting the development of women's health in general.

Further, as acknowledged by Kannabiran et al. in [26], works such as [55] illustrate the implication of design for the practices of women's health. In so doing, Kannabiran et al. note that work such as this is "much needed and can have immediate and positive effects on human life" and the impact of such work "extends beyond the individual and affects larger social concerns". In this paper we attempt to respond to this call for action by investigating the practices and processes associated with the domain of women's health, and in particular care related to urinary incontinence. Through so doing, we show how intimate care is a prevalent feature of women's health. We extend feminist HCI [8] by conceptualising women's health for the HCI community, and reveal the problems and opportunities associated with working and designing for this space.

Key issues affecting women's health include access, quality of care available, as well as the positioning of women and their bodies within society [63]. In this paper we are particularly concerned with the quality of women's healthcare and the potential for HCI to positively improve the options and experiences available to women within this context. We motivate our concern by using the example discussed in [55]: the vaginal speculum, where it is well documented that women's attitudes and prior experiences regarding examinations with this tool determine whether they have them [56]. The vaginal speculum is a medical gynecological instrument developed during the nineteenth century, at a time when women's anatomy was "largely misunderstood" [55]. It is used as a means of dilating the vagina to enable inspection of the cervix and vagina. The design of this device has seen little or no development since, in spite of advancements in technology that allow us to have a better understanding of the female body in its anatomy, physiology and morphology. Whereas this is a technology that "gets its job done" its design takes little or no account for the experiences of the women upon which it is used. While this is a test "which takes only minutes to perform [42]" it is considered to be unpleasant, embarrassing, fearful, painful, or uncomfortable by most women [67]. Studies such as [67] also challenge conventional medic/nurse-patient relationships by demonstrating self-insertion as "an acceptable, innovative, simple and cost neutral change in clinical practice that increases women's comfort and satisfaction". In contrast to [6] where the authors identify sex toys as the pinnacle of experiential technologies, we argue that the design of tools

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and techniques for women's health are the opposite, devoid of concern for the experiential qualities of care and touch, and therefore ripe for examination.

RELATED WORK

Women's health often involves intimate care work that relates to parts of the body which are considered private (e.g. genitals) or which are associated with sexuality or where the boundary of the body is penetrated (e.g. oral health). This broad definition gives rise to a number of issues, relating to how we consider 'private' parts, the sexuality of the body, and its boundaries and the relationship to acceptable (and unacceptable) social behaviours (i.e. taboo). In this section we explore the extent to which HCI has responded to notions of intimate care in women's health specifically, as well as those factors that make women's health so challenging.

Women's Health in HCI

The vast majority of work within the context of women's health in HCI is focused on maternal care. This ranges from technologies to increase empathy within partners [27], through to tools to support healthcare record management across pregnancy [21], and mobile tools to encourage healthy behaviours in pregnant women [28,52]. In addition, there is a body of work focused on upskilling and supporting midwives and health workers in developing countries [1,53,65]. A smaller volume of work has explored other elements of women's health, for example, the development of an mHealth platform to support women going through the menopause [30] and the exploration of mobile applications for reminding women to take their contraceptive pill [61]. Other work has explored the specific needs of women with breast cancer in the development of online social support systems [59], as well as tools for monitoring the systems of women with breast cancer in rural settings [24]. Systems for gynecologic exam training have been explored in [44] suggesting that medical students can learn both procedure and diagnose from interacting in a virtual environment. For the most part these devices and technologies do not situate themselves within the 'dirty work' of women's health, but on the periphery, offering advice about how to be healthy, or how to recognise labor, as well as easing the burden of sharing health records between healthcare providers. Such an avoidance of the body in issues relating to women's health is reflective of Rossman's claim [55] that the female body is taboo, and has implications for HCI in women's health which responds to and takes account of the body [26].

The Body

Historically the human body has been perceived and represented in many different ways. In the late eighteenth and early nineteenth centuries the body, its representations and routines were transformed [22]. Medical models emerged that made sense of sexual differences between the female and male anatomy and physiology. These models made their way into public discourses about the body, and, as cultural values and constructions of the body evolved,

the body became the mechanism for the explicit expression of sexual difference [23]. The body, and the associated dress, diet, and routines, became "a medium of culture [35]". With this, notions of the corporeal being as being-in-the-world [19], with perception and embodiment as constitutive elements, thereby positioned the body as a site of social production of the self. Cosmetic surgery [3] and technologies for surveillance, which can be as basic as mirrors [64], are techniques and tools to support control the presentation of body/self, both by manipulation and display.

An extensive body of work exists that address e-health technologies and the quantified self. For example [68,69] personalize fitness by collecting data on bodily functions, such as heart rate, pulse or calories burned, while [15,43] combine mobile apps with smart objects to encourage and support assisted tracking in intimate fitness, such as pelvic health. More broadly, the role of the body in HCI and designing for interactions has been explored extensively in [33,34,62], including whole-body or movement based interactions, while tangibles for promoting body literacy have been documented in [49] to further real-life (on-body, wearable) learning of human anatomy and physiology among children. A proposal that talks with and about a bodily taboo, menstruation, has been the topic of research and discussion in relation to design through research [5]. The work itself, Menstruation Machine [60], approaches a natural physiological phenomenon to speculate on alternative futures and the design knowledge of the body.

Taboo and Intimate Care

Many of the concerns of women's health (as a result of its definition) necessarily involve intimate care, from the insertion of an intra-uterine device to control reproduction, through to mammograms examining breasts for cancer, and the use of vaginal lubrication during menopause. Intimate care has been defined as, "those care tasks associated with personal hygiene, bodily functions and bodily products, which demand direct or indirect contact with or exposure of the sexual parts of the body as defined culturally by the individual [66]". The practice of intimate care is intertwined with notions of taboo. Taboo is associated with physical, bodily and social practices that are restricted from public consumption as a result of social customs within different societies. Research and design in these areas is generally considered to be laden with emotion as well as potentially risky for the individuals involved.

Recent work in HCI already explore areas of taboo that are representative of life disruptions, such as intimate partner violence, homelessness, and death [16,17,37,38]. However, as noted before, part of the taboo nature of intimate care is that it often involves parts of the body that are hidden or involved in sexual functioning, which undoubtedly is tied to its link with sexuality. The World Health Organization (WHO) defines sexuality as a central aspect of being human throughout life and which "encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure,

intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships [70]". Sexuality in HCI remains a taboo topic, even though the topic of sex has seen regular contributions over the past few years, mostly around themes of online pornography, virtual worlds, performance art, and human-robot interaction [7]. Some of the barriers that hinder research are that human sexuality is a complex phenomenon that lacks a "single universal definition", and "it is an aspect of being human that crosses various dimensions of both everyday life and academic disciplines" [26]. Sexuality is an aspect that "permeates our lives", as it extends to grooming and feeling good about oneself [7]. Similarly, intimate care also pervades our lives - it is inherently part of our everyday life - and can be closely linked to sexual health and wellbeing, sexuality, and sexual technology. Furthermore, sexual health is "the state of physical, mental and social wellbeing in relation to sexuality" [70], and it encompasses intimacy as a central aspect of being human. Much like sexuality, intimate care lacks a single definition as it entails distinct approaches to hygiene, safety and healthy habits across the lifecourse. On the other hand, while the essence of sexuality may change throughout the lifecourse, intimate care work is perceptible, to the self and/or to the other, from beginning to end in bodily health and wellbeing. Nonetheless, sexuality and intimate care research overlap in that designing for intimate care in HCI needs to support health and education in relation to bodily experiences that include, for example, continence and sexual pleasure, or self-care and reproduction.

CASE STUDY IN WOMEN'S HEALTH

We build on this previous work to explore how health and wellbeing can benefit from intimate knowledge of the body, interpersonal communication within communities, and advancements in technology. We start by giving an overview of urinary incontinence in women, and report on findings of our observational study in a women's health practice consultation.

Urinary Incontinence in Women

Urinary incontinence (UI) is generally defined as the involuntary loss of urine [25]. Although both men and women can experience incontinence women are twice as likely to experience incontinence across the lifecourse. Recent contributions to medical literature report that approximately one out of five women suffers from moderate to severe urinary incontinence [40] or that it varies in a range of 12% to 55% [12]. In women, incontinence "is neither an illness nor, strictly, a medical problem, descriptively labeled a bodily dysfunction rather than a diagnosis, a social rather than a biological pathology" [50]. For example, incontinence is generally accepted as a consequence of childbirth and/or aging. It is regarded as "normal", similarly to menstruation once a month and menopause once in every lifetime [36].

Caring for the disruption and dysfunction of UI can affect a woman deeply. Not only because it may be a bodily function that is difficult to control, which on one hand affects the social person and on the other that person's intimate relationships, it is also a mark on a life trajectory. As coping mechanisms, people abandon their outdoor habits and routines and change the clothes they wear to disguise episodes of incontinence, and women choose to constantly use sanitary towels as a method of achieving social continence (preserving independence and quality of life while managing incontinence) [54]. Nonetheless, these techniques used to manage incontinence can prevent the establishment of relationships or cause embarrassment [54]. As a result, incontinence constitutes a threat to everyday activities that requires mechanical means of protection and body maintenance, which can have an impact on social membership [50] and affect lifestyle. Since the body is a medium of culture [35] incontinence can impact on the sense of self. Nonetheless, the association of UI with childbirth and menopause, together with experts' opinions, reinforces a cultural model of UI as a normal aspect of womanly inheritance. Through normalization comes acceptance of commodities such as pads, which are easily available as "normal women's apparel" [51]. They are assimilated as part of a lifestyle, and therefore of a body in control.

Generally, women are reliant on the institution to choose medical devices for them [55]. Likewise, women must rely on a medical practitioner who can diagnose their UI to receive appropriate treatment. Diagnosing UI in women is complex, invasive and at times embarrassing. Quantifying incontinence requires women to undergo invasive procedures, such as urodynamic analysis (which requires the insertion of a catheter), within a clinical setting and rely on the results to determine whether it is "simply a bit of dribble" [51] or a condition that requires surgical intervention.

Tiers of Care: Women's Journeys to Therapy Services

In the UK, the health service is divided into two tiers: primary and secondary care. Primary care refers to the care a person might receive from her general practitioner (GP) or, for example, community physiotherapists. It traditionally refers to community based care, and tends to include, among others, preventative care (e.g. health screening, health promotion), help to self-care, or maintenance of long-term health (e.g. day to day management of stable chronic conditions). Secondary care refers to the care a patient receives in hospital, as either an in-patient or an outpatient. It involves utilizing specialist knowledge or skills, or providing more intensive care than can be provided in the community [71]. The National Institute for Health and Care Excellence (NICE) sets out the quality of care and support for urinary incontinence in women [48]. This quality standard for urinary incontinence in women states that: the woman starts her journey by first going to her doctor for an examination and incontinence

history, which will help “*identify the type of problem and decide whether referral to a specialist is needed*”. To help identify the problem, the woman is asked to fill in a bladder diary for a period of 3 days and she is advised on possible lifestyle changes that might support improving symptoms; the woman might be offered products, such as pads, that will temporarily help her manage her social continence; if referred to a specialist, she is assessed by the physiotherapist and offered 3 months of training in pelvic floor exercises as a first treatment; alternatively, she can be offered bladder training. Ultimately, in light of the treatments mentioned being unsuccessful, the woman is offered surgery or other invasive treatment.

METHOD

As noted above, urinary incontinence is an example of how a disruption to the biography of the body evokes the need for intimate care. With urinary incontinence in women as our starting point, we undertook an observational study within a clinic to understand the components of intimate care within a women’s health professional setting.

Observations

Over a period of 8 months (February 2014 to September 2014), we spent a total of 18:30 hours observing the practice of one Clinical Specialist Physiotherapist in Women’s Health, Therapy Services at the local NHS research hospital. A total of 9 sessions were scheduled, 2 of which were later cancelled due to unexpected health matters. Sessions varied in duration, ranging from a 4:30 hours to 2 hours. On average, we observed between 4 to 6 appointments in one day. This fieldwork allowed us to familiarize ourselves with current medical practices, assistive devices in use, approaches in dealing with patients, and a general knowledge of a wide range of medical conditions that relate to pelvic health care in women. During the observational study, 31 consultations were observed, 30 of which were female patients and 1 was a male patient. The standard time of an appointment was 20 minutes.

Data

Due to the context and intimate nature of this fieldwork, no audio or video were recorded. Photographic images were recorded of medical devices and white board outside the consultation room only. The data corpus consisted of handwritten fieldnotes, and all quotes are paraphrased from participant observation, and drawn from informal and spontaneous interviews with the physiotherapist, Charlotte (a pseudonym).

Study Limitations

We identify a number of limitations to this study. Firstly, our study comprises observations of 31 patients who attended consultations for varied pelvic disorders by a single physiotherapist (Charlotte). Secondly, the complexities of their symptoms were handwritten only, as observed with the consultation, with no interviews follow-up. Nonetheless, our sample was representative and diverse

for a qualitative cohort, and provided in-depth insights into a diversity of disruptions to the female body that demand for professional women’s health care.

Women’s Health and Therapy Services, Physiotherapy

The hospital where we conducted our observations has been providing healthcare to communities in the North East of England for over 250 years. The Women’s Health Unit (WH) is an outpatient unit. During the study, the WH department was understaffed, having the equivalent to 2.5 fulltime staff working in Therapy Services, Physiotherapy. The Clinical Specialist Physiotherapist, Charlotte, works part-time (3 days a week), and consults across units (gynaecology, maternity, physio). There are two consultation rooms for WH physiotherapy. This is also where Urology consultations take place, as a wall sign indicates most recently. There have been more male patients coming through for treatment lately, Charlotte has commented.

Therapies

Most of the time women arrive to the WH consultation with Charlotte after a referral from primary care, which includes a preliminary assessment by their GP. Only a few are referred from a community centre nurse.

Before attending to patients, Charlotte looks at the list of appointments she has got for the day and briefly assesses the variety of treatments she expects to deliver throughout the day. Everyday is different, and patients may be coming in for the first-time or for a follow-up consultation, with treatment for health conditions ranging from carpal tunnel in pregnancy or ultrasound therapy in post-natal women. Clinical consultations in women’s health physiotherapy are divided in three main categories: ante-natal, post-natal, and gynaecological, and the most common symptoms that lead women to seek treatment are stress, urge, and mix incontinence across the three. Other symptoms include carpal tunnel, back, and pelvic pain, most frequent in ante-natal consultations, and prolapse, which is primarily a condition diagnosed in post-natal women.

During the study, we attended seven gynaecological consultations, seven ante-natal consultations, and thirteen post-natal consultations. Each of these consultations involved an examination by the attending physiotherapist. 17 included an initial assessment (first-time patients), 4 for a follow-up on stress, urge, or mix incontinence, 6 with severe back and pelvic pain, and 4 for ultrasound treatment for perineal tear. The one male patient was a follow-up consultation related to persistent incontinence symptoms.

In the following section, we describe our findings by identifying patterns of intimate care work within a women’s health setting. The themes identified were analyzed using a thematic analysis approach [11], to give insights into experiences of women’s health, in relation to both the patient and the therapist.

FINDINGS

In this section, we discuss insights from our observations and informal conversations with the therapist regarding interpersonal relations, the therapies, and technologies in use for this practice. We start by describing a consultation, representative of the intimate care work performed by the physiotherapist, and continue to explore perceptions and experiences of patients-physiotherapist regarding the act of intimate care on the body required by the advent of incontinence.

Within a Consultation

Charlotte starts by welcoming the patient into the consultation room. She sits on her chair and looks back at the patient's information, which she has on her desk. She then starts a conversation with the patient, who is now also sitting and facing Charlotte, and this initial conversation will help her cross-examine the patient's clinical history, when this is a first-time patient, and to ask further questions concerning the patient's present-day symptoms, whether a first-time or a follow-up consultation. While doing this, Charlotte handwrites her own notes in a departmental designated paper-based form and, based on the patient's clinical history and account of symptoms, she decides on the examination that will help her make a clinical informed assessment. Typically this includes a manual exam, which Charlotte performs on patients with symptoms of stress, urge, and mix incontinence. This clinical evaluation of the pelvic floor relies on manual muscle testing with vaginal palpation, which comprises a manual and internal examination of the vagina for muscle strength and tone, allows her to understand whether the patient is able to contract her pelvic floor muscles and by how much. Technically, in women, a contraction of the pelvic floor muscles is based on the modified Oxford Grading System, a grading system to measure pelvic floor muscle (PFM) strength ranging from 0 to 5, in which 0 represents weak with 'no contraction' and 5 amounts to 'strong' [10]. By performing this exam, Charlotte is able to effectively generate an initial evaluation of weakness or strength, as is able to adjust a continuation of treatment based on improvement. The prescription varies and depends on each patient, since the prescription takes into account a women's personal biography, for example, whether the woman is making plans for a future pregnancy, or the biography of her body and any disruptions might be present, such as a prolapse. Nonetheless, pelvic floor muscle training (PFMT) is the conservative line of treatment prioritized, and unless proven ineffective or contraindicated, pelvic floor muscle exercises (PFME) are generally prescribed to most patients.

Crossroads of Women's Health Work

What brings these patients to Charlotte is ultimately a point of crisis. The difficulties in managing their own continence have intensified to a point where self-care is no longer viable. Here we describe three interactions within Charlotte's consultation room. We document the

experiences of Ellen, Kate, and Hillary (pseudonyms) while seeking therapeutic support for their 'bodily dysfunctions'.

Managing the Leaky Body

Ellen walks in to her first appointment accompanied by her husband. She is seventy-one years old, has had four children after which, later in 2011, she has had her uterus surgically removed. Referring to clinical procedures that involved invasive repair, she comments:

"They (medics) don't explain what they're doing, they just shut it up your body." (Ellen, 71)

She has been managing incontinence by keeping urine charts and wearing incontinence pads. She had also been told to do pelvic floor muscle exercises long after childbirth but has felt worst after doing them. In fact, she acknowledges that she had never understood how to do them, and had never been explained how to either. This time, Charlotte does not perform a manual exam to assess. Instead, she shows her a cross-section model of the female pelvis and describes exactly where the pelvic floor is, explains what it does, and how to exercise the muscles:

"Imagine the vagina is like a tube; start squeezing from the back passage to the front passage; do not hold your breath; squeeze, hold, count up to 10, 5 seconds, relax. Do it 3 or 4 times a day."

At the moment, Charlotte's work involves teaching and the intention is for Ellen to learn how to get her pelvic floor to work better. This care work is passed on to her, and it will require her to take control and continue exercising.

Contrary to Ellen, Kate is certain that she knows how to do PFME, and she has managed to include the exercises in her daily routine, mainly "while driving". She is 50 years old and she has had six children, the last of which was born when she was 48 years old. She is professionally active and her job requires her to do some lifting which, as a result, is aggravating her pelvic health. She feels "uncomfortable" (prolapse: her uterus is low onto her vagina) and she has symptoms of stress incontinence. During the conversation, and after looking at Kate's clinical history, Charlotte informs her that she has had three different areas of prolapse, likely heightened by her later in life pregnancy. But Kate is not aware of the particulars that caused a disruption to her body. Similarly to Ellen, her comment is that *"they don't tell us anything"*. Charlotte chooses to perform the manual exam on Kate. She suggests doing so while pointing out that such examination is the necessary course of action for her to finally determine what is wrong and what to do about it. Kate seems agreeable, does not ask any questions about the procedure, and promptly stand up. The examination entails Kate moving to the other end of the consultation room. The room is divided by a wheeled screen, behind which she removes her clothes, after which she lays down on the examination table, facing up. Without hesitation or further explanation, Kate does so and is promptly ready. Charlotte finishes her notes at her desk and

once knowing Kate is ready (through conversing across the dividing screen) she too proceeds to the other end of the room and prepares for performing the exam (she sits in a low rise stool and puts on surgical gloves). Kate takes a comfortable position, legs flexed apart knees bent, and Charlotte explains her the procedure while beginning the internal examination (manual vaginal palpation, for which she uses one finger to evaluate pressure, duration, muscle structure, displacement), the technique currently used by most physiotherapists to determine qualitatively whether or not there is a muscle contraction [10]. This involves Kate contracting her PFM as hard as possible, to sustain a contraction, or to contract and release instantly and repeatedly, as requested by Charlotte, who at the same time evaluates and quantifies strength while giving Kate feedback on her seemingly ability to perform well. Kate does manage to exercise accordingly and, after repeating the exercises a few times, this is enough for Charlotte to realize that Kate has a good pelvic floor muscle, which is what “*is keeping everything inside*”. Initially, Charlotte starts by recommending the practices of Yoga or Pilates as way of promoting regular exercise to help maintain good pelvic health, but ends up recommending her to surgery, the final course of action in the line of treatments available, which will fix the body internally so it stops leaking. It transpires that this is what Kate “*was hoping for*”, Charlotte comments after Kate has left the consultation. Nonetheless, this bodywork (surgery) requires invasive procedures that some women would prefer to avoid. One example is that of Hillary, she has a third degree prolapse, which is making her bladder ‘come forward’ and descend out of her vagina. She hasn’t been suggested surgery yet and Charlotte hopes to understand, by performing the manual exam and assessing her pelvic muscle strength, if PFME could help. Like Kate, Hillary’s job is demanding of her body posture, requiring her to be standing all the time. While the pelvic floor “*works against gravity, and it is working all the time*”, Charlotte informs her, Hillary’s pelvic floor muscles are very weak which is causing the prolapse to “*bulge out*”. Hillary questions:

“Is it a problem with people this age?” (Hillary, 51)

Moreover, information regarding preventative health care practices, such as pelvic exercises, is normally unheard of before critical symptoms lead women to seek therapeutic assistance from a professional body. Hillary comments:

“I’m thinking, I’m going to be 52 and never done anything, now I have all these appointments!” (Hillary, 51)

The absence of knowledge regarding their bodies and the path that led them to arrive in Charlotte’s consultation is apparent mostly throughout. Moreover, Charlotte considers that “*some women have very little awareness of their bodies*”.

Taboo of Bodywork

Little awareness of the intimate body and the bodywork associated with it is a barrier for intimate care, for example, the fact that it often involves parts of the body that are hidden, involved in sexual functioning or human waste contribute to physical and cultural taboos associated with it.

By way of example, we describe the bodywork received by post-natal women who were prescribed with perennial ultrasound as a line of treatment. A perennial tear is common during childbirth, and it can heal naturally or, if more extensive, require surgery. A perennial ultrasound is provided for post-natal woman who have had a significant perennial trauma. Treatment involves a two minutes pelvic massage to soften scars with ultrasound, over the course of ten to twelve sessions to be effective, and it usually takes up to three sessions for any improvements to start showing on the soft tissue. The procedure, much like that of the manual exam, is straightforward: Charlotte covers the examination table with paper and makes sure everything else is in place before the woman enters the consultation; once the woman comes in to the room, they converse; the woman removes her clothing behind the screen that divides the room: desk with computer and chairs on one side, table for treatment on the other; Charlotte finalizes her notes at the desk; the woman is laying down on the examination table, and uses a towel to cover her pelvis; Charlotte redirects the light fixture hanging from the ceiling to shine on this woman’s perineum, she puts on gloves, covers the ultrasound device with a condom and adds some gel to it: this is the surface which will be in direct contact with the skin of the woman.

During our observations, a total of four women had follow-up appointments for an ultrasound. Being a continuation of a treatment already started, all four women were already acquainted with Charlotte, just as Charlotte was with them. The sessions did not present any difficulties, for example, in one appointment the patient and physiotherapist’s talk was amicable and lively throughout the treatment. Generally, it is Charlotte who drives the conversation. Moreover, she minimizes the awkwardness of this setting by stressing therapeutic facts, such as that the perineal injury is visibly improving or that the scar might feel more sensitive due to the menstrual cycle, all acceptable informed knowledge that helps normalizing the experience.

Women’s Expectations

After an examination Charlotte discusses a treatment plan with the patient. The most commonly prescribed line of treatment for women with symptoms of incontinence is pelvic floor muscle training (PFMT), which aims to improve pelvic organ support (e.g. bladder) and increase control over pressure on the pelvic floor. The prescription is typically based on an amount of exercising a day, which, once assigned to the woman, she will need to assume responsibility for and be proactive about, by doing it at her own time, and by incorporating it into her daily life.

Finding the time to do the exercise or remembering to do it are major concerns identified by some of the women. *"Life gets in the way"*, Ava (pseudonym) comments. She sits in the consultation room for her follow-up with Charlotte. She has a long history of incontinence and her last examination had been six weeks earlier. Her treatment includes pelvic floor muscle exercise three times a day, which she forgets, she has *"too much to do"*. Charlotte recommends the use of visual reminders, such as putting a chart on the wall or on the fridge. PFME is also more difficult to fit in (the daily live) then doing it. Charlotte remarks:

"If doing it right, no one should notice that you are doing it."

PFME can be incorporated into a daily routine, for example, *"while driving"*, or *"while brushing your teeth"*. Understanding the technique is key, and once it is incorporated PFME can be done anytime and anywhere. The intimacy of this practice involves its invisibility to others, making it self-empowering as the woman is confident to be doing it correctly, hence working toward her personal health.

As noted before, recommendation for surgery is seen as the final solution for incontinence. Charlotte sees a great number of women who go through a series of regular appointments that include GP, gynecology, and physiotherapy, until they are 'approved' for surgery and give their problem a final solution. In contrast, in the case of Hillary, who we have discussed earlier, she is not yet ready for a surgical solution. She has a third degree prolapse and just started looking for the adequate treatment. She asks about pessaries, which are medical devices used internally to provide structural support (or as a method of delivering medication), as an alternative to surgery. Charlotte informs her that they are not usually considered an option or generally recommended within the NHS, they are more commonly used in the US and Canada. She also comments on the fact that some people can't retain them, and they just keep dropping. *"It's usually difficult to find a shape that adapts to the women's body, it's a lot of trial and error"*. Besides, *"women don't generally know their bodies in ways that help them fit the pessary easily"*, referring to the possibility of having the woman inserting and removing her own device whenever needed instead of having it done more permanently in clinic.

From Charlotte's Standpoint

While Charlotte performs mostly a manual exam on her patients, there are a variety of medical devices and tools that can also be used within her practice, such as the ultrasound mentioned earlier. Commonly used items include a variety of specula, probes for biofeedback (to assess whether the patient is able to perform a correct pelvic floor muscle contraction) or electric stimulation (to gain a better understanding of existing muscle movement), dilators (for cases of overactive pelvic floor), and vaginal cones (to assist in PFME).

Charlotte shows us some of these devices that she keeps in a medical supply cabinet. She describes the *Sims speculum*, which is the medical device usually used to check prolapse. This is not a device that she uses very often in her daily practice however she is trained to use it in case of need. The device makes her feel *"uneasy"*, due to the required technique of use: the woman patient needs to be lying down and sideways, and the physiotherapist needs to insert the speculum while standing behind her. Much like the vaginal speculum, which gets its job done, it is designed to be ergonomic for the people using it rather than the people receiving it. Charlotte remarks that it is a *"very dominant position"* (she finds herself in while performing the examination). It *"feels like I can do whatever"* as the patient is *"very submissive"*. The fact that there is no visual contact and that she can't look at the face of the patient also works as an obstacle to engage in a conversation. Furthermore, she is in the opinion that these instruments, available for therapeutic evaluation, are *"in much need of redesign"*, as she admits that discomfort, a sense of vulnerability and a sense of undesired control (or lack thereof) during such examinations occurs from both ways of using the speculum.

According to Charlotte, more than 50% women who have had a delivery have a small prolapse, but this does not affect their daily life. Nonetheless, women want *"to be perfect"* after delivering, she comments. But there is *"no magic cure"*. Nonetheless, some women describe symptoms such as a constant feeling of wanting to *"go home and get changed"*, an urge to *"go to the loo"*, or that it *"feels like something is going to fall out"*. These are understood as serious enough symptoms since they affect daily routines and quality of life in general. Moreover, the care work involved in improving such symptoms include bodywork that needs teaching and learning from both cared-for and person giving care, as each biography is unique in its disruption. Overall, the pelvic floor muscle is *"an anticipatory muscle and it can be a lazy muscle"*. When *"trained"* it *"works automatically"*. Thus, it is bodywork that entails a lifetime of fitness. Whereas within a consultation Charlotte assesses and examines the biography and the body to understand the disruption, the patient relies on Charlotte's judgment and expertise to help with her symptoms. The prescription varies from patient to patient, as do results based on patient's compliance with the treatment. There is no *"magic wand"*, she remarks. It is the patient's responsibility to follow through with her prescription, which she cannot oversee (unless and until there is a follow up appointment) but only recommend.

DISCUSSION (DESIGNING FOR WOMEN'S HEALTH)

In our case study of women's urinary incontinence we introduced a life disruption centered on the body and presented findings from our observational work, which was conducted within a women's health physiotherapy consultation room. Our findings highlighted that bodily interventions in women's health, whether on the self or the

other, involves body literacy, concern, confidence and mutual trust. In our discussion, we expand on the role that HCI can contribute to improve women's health and opportunities for digital technology to improve women's experiences and practices around women's health.

Women's Health as Life Disruption

Despite the apparent continuity of the body as a site for the self, the body has also been understood as a site in flux. As argued by [58], the body is a fabrication, it is "organised not according to an historically progressive discovery of the real, but as an always insecure and inconsistent artefact, which merely mimics material fixity". Marked by a deviant state, such as being ill or unhealthy, it is then characterized by a lack of bodily control, a way through which the body can reflect its biography. Disruptions to the biography of the body can occur at any time and they are made visible in different ways. While symptoms might be similar, treatments might vary depending on personal life story, for example, if involving family planning (decisive when and if considering surgery). Some other examples of disruptions to the body are that of loss of a breast or a limb, which affect "not simply corporeal integrity, but also the sense of who we are" [58]. Both have a massive impact on one's self-esteem, body image, and intimate relationships [39, 57]. We recall the patient who feels that something could 'fall out' off her body at any given time, and how that potentially impacts her daily routines, creates anxiety, and makes her move about differently. Furthermore, the magic wand Charlotte refers to is nothing but a desire expressed to make perfect something that is primarily invisible to others, but yet can be vexatious to the self and in intimacy with others. Other disruptions and dysfunctions to the body, like infertility and menopause, raise questions about gender, and provoke social embarrassment [36]. Dysfunctions related to the aging body revolve around bodily difficulties such as mobility and continence, and bodily esteem may disappear at an older age [64].

On Knowing

As we see when Charlotte explains the subtle technique of exercising the pelvic floor to Ellen she is sharing and transferring knowledge of the body that in turn extends Ellen's own understandings deeply. So much so, that something Ellen had never perceived before throughout her lifecourse was now made tangible by Charlotte's descriptions on a visual model of the pelvis. In our experiences on the ward, we see a number of appointments such as this, and through this how body literacy is paramount to support timely preventive care practices on the body i.e. having knowledge of and knowing how to care for one's own intimate anatomy can potentially safeguard future health. Taboo, misinformation, and lack of self-awareness of our personal bodies can be a hindrance to provide self-care as much as care for the other. Moreover, the lack of information or misconceptions about the disruptions happening on their own intimate bodies is recurrent among the majority of Charlotte's consultations.

One outcome of these appointments for each patient is an opportunity to learn more about their own bodies, their intimate anatomy. Yet, it is striking that it appears to take the life disruption of urinary incontinence, and quite often the intimate care of another woman, for a woman to establish some form of body literacy. And, although through this act of care the women do learn something about their body, this learning is second hand. There is little visibility of the knowledge gained by Charlotte through her examination, or attempts to pass details that would enable a women to examine her own body to detect and track increasing strength in her own pelvic floor muscles. A system such as the transperineal 4D ultrasound might serve to assess PFM damage [45] and provide visual feedback on screen of what a therapist sees and does during an examination. Yet the therapeutic ultrasound for post-partum perineal tear within this clinic does not have a display. Systems such as AnatOnMe [47], a medical handheld projection device have made use of augmented reality to project onto the patient's body a variety of bone fractures. Expert interviews in relation to AnatOnMe suggested that such AR projects would help a physiotherapist teach parts of the anatomy relevant to the injury, the bio-mechanics of the affected area, as well as the signs and symptoms of the injury, rationale of treatment, and physical therapy goals. We ask, what would it be like for a woman during an internal examination to view on her body a 'reality' of what the therapist is feeling and experiencing? A system such as this, designed to enable a woman to view the anatomy and biomechanics of their vagina and pelvic floor muscles during an examination may well similarly create opportunities for more effective and engaging conversations about a women's intimate anatomy that supports and fosters better body literacy and (self) caring practices.

There were no explicit displays of emotion during the consultations we observed, and since we were not able to interview women directly about how they were feeling before or after their consultations we cannot categorically say how these women were feeling during their examinations. However, qualitative research on women's experiences of smear tests and internal examinations would suggest many were feeling anxious, embarrassed and uncomfortable [42]. Given these negative emotional experiences, we might question whether additional learning during a consultation would be the most effective way to help women develop literacy about their own body. This brings us to consider whether there is potential in the creation of artifacts through the examination procedures that might enable learning and literacy afterward. A small body of work has explored the creation of souvenirs to mark 'rites of passage', such as riding a terrifying rollercoaster [20], through to 'sonic souvenirs' [18] of family holidays. There is an opportunity for HCI to similarly explore the extent to which 'souvenirs' of intimate women's health examinations and check-ups might be created. On the face of it, this may be a strange souvenir to

possess. However, creating and providing these souvenirs could enable a woman to explore her own body, at her own pace in ways which don't provoke shame, taboo or discomfort. And, through so doing empower a woman to come to know her body in ways which support prevention, maintenance and remediation.

Each of these provocations suggests ways in which examinations might be augmented to enable increased body literacy among women during routine or responsive appointments. However, what these approaches do not do is tackle the social and societal discomfort that leads to this lack of literacy in the first place, i.e. the taboo associated with a woman's body [55]. Critical design is one approach that has worked toward making visible the female body in all its guises. The Menstruation Machine [60] is a critical wearable design provocation that replicates the experience of menstruating and interrogates this bodily function as desirable in a foreseen future. 'Kegel Organ' [32] is a response to a wearable technology studio brief to designing for body parts that are usually forgotten or neglected. Additionally, art-based interventions such as The 'Great Wall of Vagina' [41] contribute to create generalized awareness of body taboos by elevating intimate body parts, typically confined to one's private realm and removed from public view, to the white-walled gallery and media spotlight. At an even wider level, social media can and does play a role in 'breaking down the barrier of taboo', and particularly as a vehicle for promotion of preventative health practices. For example, the cervical cancer campaign 'Smear for Smear' [75], has aimed to create a wider awareness of the importance of smear tests and encourage younger women in particular to be tested. Alternatively, as a platform to support reclaiming the body, women have 'live-tweeted' menstruation to restate embodied identity in response to the public derogation of women [76].

On Care Prescriptions

Charlotte recommends an NHS approved PFMT app [46] to her patients, which describes how to do PFME and reminds a woman, through alerts on her phone, to undertake her training according to an agreed (in consultation) schedule. Technologies such as this are available for free or at a small cost, and suggest a relatively recent proliferation of women's health interventions within the public sphere. These apps often aim to promote women's health and intimate care by building capacity by engaging with and supporting healthy behavior over time. Common topics include menstruation diaries, pregnancy trackers, and contraction timers. However, these apps might be viewed as exacerbating the disembodied understanding of the self and intimate parts of the self, since they may disengage one from their body. Evaluation of designs that push the boundaries of *self-knowledge* and *knowledge of others*, all the while considering a cultural taboo as a design material, was recently introduced in [5], and the design of *Labella*, an intimate wearable for self-learning about hidden parts of the female body, has been presented in [2]. The latter also

shows how technology can contribute to breaking down the taboo to help reduce the barrier of self-care, by suggesting that the notion of taboo around this body space might benefit from the support of embodied technologies to encourage looking at oneself. Moreover, projects such as [9], which promote continence care in the community with a focus on reducing social stigma, point out the need for establishing and improving relationships between patient and clinician and the way in which decisions are made. By considering body-worn (smart underwear) and on-body (colour change odour detector) devices it is suggestive of moving forward mechanisms that would support the individual in managing their incontinence in everyday life, by notifying them of leakage or body odour, for which they are alerted and can take prompt action. Similarly, mobile apps and 'smart' objects that support PFME [15,43] point towards the raise of individual responsibility, serving as a reminder to exercise which, of course, only the woman can decide whether she complies or not. In this regard, technology has the possibility to support not only remembrance but also fitness tracking. However, technology that supports making this intimate workout visible, i.e. talked about, visualized, or shared in collaborative networks that may support development and lessen the taboo of looking at and knowing about oneself, is withdrawn from clinical settings just as much as digital technologies available for the individual. We therefore suggest that wearable and mobile systems for women's health and intimate care consider the implications of these experiences, i.e. preventing, maintaining, or remediating incontinence, generally enacted alone, and recognize such as a positive challenge to HCI design, to negotiate privacy boundaries and succeeding acceptability of technology, and an opportunity to innovate in, for example, wearable sensing (e.g. smart textiles and analysis on wear or fitting) or encouraging exercise in public designated spaces (e.g. implement a data logging system for measuring PFM strength in specialized gym equipment). The latter could include elements of competitiveness, as data could be shared to encourage gamified learning.

On Taking Charge

Charlotte's prescriptions, which typically include pelvic floor muscle training based on an amount of exercising a day, rely heavily on the self to succeed - both in terms of knowing how to exercise, and remembering to exercise. It is based on this individual responsibility, the transfer of power to care for the self, that the outcome of health is made visible. Furthermore, knowing and remembering to care for the self does not solely need to be framed as a remedial activity, or one of maintenance, but also one which reduces the need for formal care interventions. An interesting example of (not) 'taking charge' that we encountered in our observational studies was the case of the pessary. Here, a woman who is aware of her body can have the option to insert and remove the device when in need and without clinical intervention as one way of controlling

urinary incontinence. However, Charlotte is reticent to prescribe such measures, noting that the NHS rarely make use of these interventions in part because women have difficulty fitting them correctly. We can clearly see the entanglement of knowledge of the body to women's health, and the problems that arise in proactively caring for the self when body literacy is insufficient.

Reliance on the self and on others is marked by a shift, and new frontiers need to be re-scripted. Nevertheless, the intimacy involved in this bodywork may require embodied interactions that benefit from self-knowledge or tangible interactions that require manipulation and touch by others. At a time in which the woman patient is mostly reliant on and becomes subjected to the institution to choose the medical interventions that will offer her the best care and comfort, empowerment occurs when alternatives to the existing status quo support her in becoming the subject of her response through learning and promote trust across the personal and professional communities. Technology use and design impacts the nature of the outcome of subjectification [6], and by examining the asymmetry highlighted in our qualities of intimate care within HCI research we open the discussion that place life disruptions, such that of the body, as a future lens to relate to possibilities of intimate technologies.

Technology has a profound mediating effect on the way we relate, obtain knowledge, and contribute to society. Most technologies configure their user as a consumer and not as an active participant, and the rise of DIY (Do-It-Yourself) approaches to what once was inaccessible or institutionally bound technologies create opportunity for change. A study such as [4] proposes an alternative approach to finding places to breastfeed in public spaces by empowering members of the community, presumably sharing similar concerns, to contribute their knowledge by reviewing locations on a mobile app. While women are reliant on members of the community to leave accurate reviews, it is also an example that demonstrates how a work of social computing benefits a personal, individual act, while empowering a community of women as activists for personal wellbeing. Other such example is 'The Great British Public Toilet Map' [72], which complements TACT3 research [25] and provides up-to-date information on UK's public toilets in a designated area, to both support people in finding facilities and "encourage local authorities to provide an maintain public toilet information as open data and in a cost effective way".

But, there are more radical opportunities seeded within DIY communities and HCI literature that could offer new perspectives of women taking charge of their intimate health. DIY practices have already been explored to introduce opportunities and concerns for HCI [29], and as tinkering outside professional settings proliferates, supported by the advent of open source, it has led to new approaches to design science and its apparatus. One

example is that of DIY gynecology, headed by [73] who develop open-source tools for DIY diagnosis and first-aid care in support of women to take control of their reproductive health, and recently [74] developed a 3D printable speculum, which aims "to democratize and "liberate" the instruments and protocols used in obstetrics and gynecology to allow low-cost diagnosis" [13]. Can we imagine then, it becoming the norm for women to conduct their own pap smears at home at timely intervals, or at times when they are concerned? And, if we can, how do we imagine women dealing with and making sense of this intimate data? Crowdsourcing of such women's health data could be one viable alternative for coping with disruptions to the body as well as seeking social and expert support from others. For example, if women are happy to share health information in an online breast cancer community [56], places to breastfeed in public [4], or information about their menstrual cycles [14] then maybe we can also imagine women sharing the results of their home-based cervical examinations, or pap smears with the 'crowd' to help interpret the data. Such innovations open the potential for innovation in women's health, and potential disruption of women's health practices globally. For example, while we see GaudiLabs currently developing 3D printing templates for a traditional speculum [74], perhaps through the community's practice and self-exploration we will see 3D printing templates come available that improve women's experiences on this front, relegating the traditional and troublesome speculum to the past for good.

CONCLUSION

Using a case study of intimate care within women's health – that of urinary incontinence - we have shown how women's health is often linked to a diversity of disruptions to the body that demand for professional intimacy of care and continued self-care. Yet, we also show how lack of body knowledge bounded to taboo come together to create conditions which lead to a diminished health experience. There are numerous existing technologies and systems which have the potential to vastly improve women's experiences of these health transactions, from tools to better visualize and talk about the hidden parts of the body, through to DIY communities which share and analyse the outcomes of home-based examinations. Yet, despite the discrepancies in healthcare outcomes HCI has contributed little to this space. To help CHI be '4Good' HCI then should stop being embarrassed about the female body and start responding to this global concern.

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