# 'Us, the Body:' Two Women's Uses of Health Texts In Hawai'i Sondra Cuban

ABSTRACT The researcher analysed two women's uses of popular culture texts on the island of Hawai'i. They read these texts in order to learn about, and manage, their health problems. These vernacular texts were different from the institutional texts that were prescribed to them by their doctors, as well as the commercial ones that were in the literacy programme they attended. Their uses of these self-help texts reflected the staunchly religious community where they lived, as well as the post-welfare society, with pressures to solve their own problems. The researcher used ethnographic methods to learn about these issues. These popular materials provided the women with relaxation and meaning, which fit with their communities of practice. The study points to the value of knowing about learners' social practices for policymaking and the importance of incorporating these types of texts into programmes.

#### INTRODUCTION

During a two-year period, I lived and worked in a town on the island of Hawai'i researching the lives and literacy practices of ten mid-life local women (of Hawaiian, Portuguese, Japanese, Filipino, Mexican, Chinese, and Causasian ancestry) who attended a learning programme in a library. The aim was to learn about the literacy practices that emerged from their life histories and their current environments, and then analyse the differences between these community-based practices, with those institutional ones that were embedded in the many public agencies they encountered (health care, library, social services), and how they negotiated them. Two of the women exemplified many of the health issues of the other women and they were selected as case studies. Gloria was one

of the women. She viewed her spirituality as imbued in her physical being. She stated, 'Us, the body, we're the church. You're the church itself...church means we're sharing, we're having fun, saying how healthy we were, or, we're bad time. Maybe we start to pray. But we have information. Everyone has information if they only could tap on their information.' Lourdes, another learner, felt a sense of affinity and safety through reading her purse-size Bible to feel protected by God, '...who is always there to help us if we ask.' These sources were touchstones for the women, to unearth their cultural wisdom, their experiential or tacit knowledge, and their emotions, leading them to tune into their symptoms and better survive them. The fact that these women, and others like them, turned to these alternative sources, after experiencing failure in the medical system, signaled a need to incorporate alternative perspectives on health and literacy to explain how and why some women learners in Hawai'i confronted their health problems.

In this article, I first present the general context, the changing landscape of Hawai'i, where I undertook this research. Second, I present the critical vernacular theoretical frame as a way to explore the women's complex stories. Third, I present the literature on health literacy which explores the textualised and non-textualised ways in which adults learn. Fourth, I present the methodology. This is followed by two profiles, after which I present my key findings and undertake an analysis. I end the article with practical and theoretical implications for literacy learning.

#### CONTEXT OF HEALTH ISSUES IN HAWAI'I

At the cusp of the 21<sup>st</sup> century, the island of Hawai'i was undergoing tsunami-like changes due to the demise of the sugar industry, causing many people to lose their jobs

and retrain for the service sector, mainly, in tourism and retail. A learning centre was set up in the local library to transition people into the new economy, and to teach them Standard English, technology skills, and, basic literacy skills. The programme's emphasis represented cultural changes since the majority of people on the island spoke Hawai'i Creole English (commonly known as, Pidgin). They had few technological learning opportunities, and, they had considerably low literacy levels, according to state-developed literacy surveys (Berg, 1989; County of Hawai'I, 1995; Omnitrak, 1989). The programme comprised a mix of English language learners (ESOL), and literacy learners, at varying levels, who used the computers in a self-directed way, and were sometimes tutored. The curriculum consisted mainly of commercial software and workbooks.

At the same time that the pastoral way of life was dying, so was welfare. A new national mantra of 'personal responsibility,' swept the mainland, and hit Hawai'i as part of the neo-liberal discourse, encouraging individuals to solve their own problems through the labour market and increasingly privatised social and human services (Field, 2006; Fairclough, 2000; Tomlinson, 2005). Overloaded social workers dropped clients from their rolls, and, in manipulating the self-determination values of Hawaiians, referred people to newly designed self-help types of job programmes, like the learning centre, ordering them to improve their skills and opportunities. The few public services, like health care, were undergoing intense marketisation, which included introducing more paperwork and increasing social distances between patients and doctors. These trends conflicted with traditional Hawaiian and local values of helping and caring for one another (Meyer, 1998; Kelly, Nakamura, & Barrere, 1981).

The local churches, however, transmitted traditional Hawaiian values (like the ones mentioned previously), seamlessly, by encouraging their congregations to strengthen their faith. They used oral methods (preaching and counseling on spiritual issues), technology (advising members to watch and listen to spiritually-based shows) and sacred texts (the Bible). The missionary heritage accounted for why churches have influenced public opinion in Hawai'i's communities, and continued to do so into successive centuries; early missionaries in the 1800s designed a mass movement to convert all Hawaiians to Christianity, including training Hawaiians to be ministers, creating many adult education opportunities, and co-opting the Hawaiian language, turning it into script (Kelly, Nakamura, & Barrere, 1981; Salice, 1991). Today, these sacred reading practices (i.e. the Bible) are like 'bibliotherapy' (reading for therapeutic reasons), and significantly different from the secular practices of public institutions, like health care facilities, where individuals are expected to read pamphlets in Standard English, for factual information (Rowland, 2000). Also, the oral-based reading of the Bible in churches (Moss, 1994) appeals to local culture, and attracts those people with low literacy levels, making reading relevant and accessible (Isaac, Guy, and Valentine 2001; Fitzsimmons, 1991; Lakes & Lewis, 1990).

But there were other reasons for why the churches were popular. The many small churches, some of which were in makeshift sites, were often the centre of social life for the many residents seeking succor from the difficult economic transition, and most of the women that attended the programme referred to their churches and God, as part of their social support systems. The churches seemed to emerge in the neo-liberal context, as even stronger than before, with their role to preserve Hawaiian and local culture and contest

the materialism of the new service economy. Ministers preached about the encroachment of Walmart, seducing residents to consume foreign goods. Churches were also protective of members who lost their welfare, offering them odd jobs, and, encouraging them to integrate into the religious community to receive its many resources (material, emotional, social, informational). All of the churches' activities, including its literacy practices, were promoted as a way to cope with these changes.

If the women's narratives had not referenced these religious sources so strongly, as helping them with their health care, it would have been easy for me, the researcher (who was not religious), to write these off as trivial and indoctrinating. These were important themes, however, that were illuminated in two women's stories, as they struggled to learn computer skills, and read, write, and speak Standard English (they spoke Pidgin at home and in their communities). The women turned to biblical electronic and print sources for healing their bodies, which were seen as infused with spirituality.

### THEORETICAL FRAMEWORK

A critical vernacular perspective (a folk and holistic belief systems framework that challenges conventional biomedicine), as defined by Bonnie O'Connor in *Healing Traditions* (1995), was needed to explain the women's complex stories about their health problems, and the ways they tied in to their literacy practices, cultures, and emotions. A critical vernacular framework focuses on people's subjective experiences of their health problems, and their meaning-making, within the context of their cultures, and why they may use alternative therapies for healing (Baumgartner 2002, Courtenay et. al., 1998, Greenberg, 2001, Kerka, 2002, Fadiman, 1987, O'Connor, 1989). This framework is also

referred to as a Health Belief Model (HBM) (Doak, Doak & Root 1996). The HBM highlights people's belief systems around their health, and how these are affected by their relationships and their interactions around their health; patients and providers are configured as 'sentient actors' responding to one another in an egalitarian, supportive way (Tanner, Benner, and Waerness 1996). This relationship becomes the basis for healing. Furthermore, the HBM highlights the interior aspects of healing and the learning that occurs in this process (Courtenay, Merriam, Reeves, and Baumgartner 2000).

The body, according to this system, is considered holy and communal rather than utilitarian and individualistic. Gloria, as we recall, stated, 'us, the body, we're the church.' Gloria had a holistic view of health, and viewed categories like, medical, biological, and spiritual, in flexible and relative terms (Ward 1999, p. 204). Healing and health, from this perspective, is viewed as a process, with, small, personal rituals and quiet indirect methods.' (Ward, p. 204). More gentle, subtle therapies may be preferred by people, over invasive or aggressive techniques (Payer 1988). Meditation, herbs, intuition, guided imagery and mantras, or communing with nature for treating ailments may be relied on over formalised systems of care that divide mind from body and separate and individualise health problems. From midwifery to magic, women's health care might emulate the practices of mothers and grandmothers and include nutrition, diet, and exercise that are undervalued by the medical establishment (Davis and Ingram 1993). It is critical to acknowledge that people may trust alternative sources not within the mainstream and that these sources be respected (Adams 1995).

Yet they are not respected in many institutions. Hawaii for example, has a long history of deficit-oriented education for both children and adults, in its neglect for the expertise and knowledge that already exists in the community (Kana'iaupuni 2004). Hawai'i's educational institutions have a history of forbidding Hawaiian from being used. Even today, many of these institutions (like the library's learning programme) enforced Standard English and forbid Hawai'i Creole English (HCE) from being spoken, even though it was used everywhere in the community. Learners were expected to learn official or mainstream (and by virtue, the US mainland) knowledge, with computer-assisted software programs and commercial grammar texts from Texas. In a region like East Hawai'i, with small, permeable domains, and, a local, shared, working-class culture, community-based collaborations could have flourished with learners moving between agencies, with their first-languages flowing across boundaries (Jacobsen 1996; Lave and Wenger 1991, Wilson 1993). Yet this did not occur. Educator Manu Meyer (1998) explains why context is important: 'Place matters... in cultural terms of continuity, spiritual purpose, responsibility, and geneology.' (p. 86). According to Native Hawaiian belief systems, Meyer, elucidates, distinctions between body/mind are unseparated from knowledge, 'liver is where you digest the powers of perception. Digestion is not purely physical. It is an internal digestion. If I have digested a book, I've eaten it, digested it ' (Rubellite Kawena Johnson, in Meyer 1998, p. 126). Therefore, culture needs to be at the foundation of the curriculum for learning to occur.

## LITERATURE REVIEW OF HEALTH AND LITERACY

A vernacular framework for health fits well with vernacular literacy practices, which are the ordinary ways people use reading and writing in their local communities for

everyday communication purposes (Papen 2005). The social practice view of literacy holds that text-based practices (print and electronic) are indicative of people's socio-cultural contexts and histories, as well as larger social changes taking place in the world, like the globalisation trends previously discussed. Text-based practices, are sponsored by various institutions and through relations of power. Schools, and other educational institutions, for example, promote academic literacy, and focus on improving literacy skill levels in individuals, so as to increase their economic opportunities. Outside of institutions, like schools, community members may engage with other forms of literacy, which are mediated by community members, and for different purposes, ones that are more culturally-based and local.

This social practice view of literacy is considerably different from the functional form of literacy that is promoted by institutions, like managed care, and literacy programmes which consists mainly of quantitatively-based research (Shohet, 2004). The social practice model, on the other hand, has its roots in ethnographic research on health (Robinson-Pant 2004; Papen 2005). Let's take a closer look at both types of health literacies.

## Functional Health Literacy

Functional Health literacy (FHL) is defined as, 'the degree to which individuals have the capacity to obtain, process, and understand basic health decisions (Selden et al 2000). It means being able to read, write, and understand medical and public health texts, like prescriptions, signs in hospitals, and doctor's instructions. First coined in the mid-1970s, it has since expanded and become a major agenda in public health and medicine, with

pharmaceutical companies like Pfizer, as well as managed care, promoting it. Health literacy is framed as an instrumental, clinical problem to solve through frontloading literacy skills into low-literate individuals, assessing them to determine the best way to communicate, and lowering the sophistication level of medical texts.

Yet it does not address the patients' needs, nor, their prior learning and knowledge, the authorities they trust, as well as their self-care, and, therapies they already use. The aim is the transmission of bio-medical messages from doctor to patient, not the use of indigenous health resources of the community. Health and literacy are turned into commodities that can be traded on the care market (see, Gee 1996, Baptiste 1998, Waerness 1996). The emphasis is on making the patient more compliant so that they will adapt to system demands, hence, *functional* health literacy. Uta Papen (2006) investigated health literacy issues in England, and found that health care environments are saturated with texts, which are often difficult for patients to read or understand. She recommends that health care professionals become better mediators of these texts, over and beyond providing simple translations or interpretations. Moreover, health care environments need to be aware of the health care resources in patients' communities.

## A Social Practice View: Health Literacies

From a social practice view, health and literacy are viewed as part of people's social and cultural histories, and the focus is on many types of health-related materials, not medical texts alone. The aim is to remove the 'clinical gaze' of the medical profession, and the diffusion of its messages, and focus instead on the social and cultural construction of the problem, and the experience of the illness, from the vantage point of

the patient. Health literacy, would mean being able to handle a range of health messages, manage personal health, and critically analyse the health care system. It would also incorporate health care barriers, including, age, gender, class, and race discrimination (Hull, Mickulecky, and St. Clair 2003; Nutbeam, 1999).

Medical ethnographies (Bloor, 2001) contain insights about health literacy issues. Ann Fadiman's study of a Hmong family in the US, dealing with the medical system, chronicles their discrimination, and the inability of doctors to accommodate their cultural belief systems about epilepsy. The doctors' demands for the family to fill out paperwork, read prescriptions, interact with them through medical charts, and, record-keeping were unrealistic and even, dangerous. Doctors did not ask the family basic questions, as anthropologist, Arthur Kleinmann would have recommended, like: What do you call the problem? What do you think has caused the problem? Why do you think it started when it did? How severe is the sickness? What do you fear about the illness? The family saw their daughter's illness as part of a spiritual malady, and the doctors, with their own cultural biases, worsened the problem by forcing treatments that were met with noncompliance. Kleinman warns, 'if you can't see that your own culture has its own sets of interests, emotions, and biases, how can you expect to deal successfully with someone else's culture?' (in Fadiman 1997, p. 261). Miscommunication is a common theme in these medical ethnographic studies. Over and beyond miscommunication, Anna Robinson-Pant (2001) conducted a study of women in a health literacy course in Nepal. She found that women learners resisted the values embedded in the course content, and their attitudes went unchanged because it did not fit with their cultures. The course designers did not understand the women's uses of literacy in the community, nor, their

health belief systems. The family planning focus was interpreted by the women as causing problems between themselves and the other women in the family and the issue was considerably more complex than the aim of the course content. The women only gained confidence in learning to sign their names, but did not adopt western practices of health. These studies illustrate the different health care trajectories of patients and medical professionals, and the importance of matching cultural contexts and communication preferences of patients so that their health care problems can be addressed in appropriate ways. The social practice literature on health fit well with the ways that the women in this study healed themselves, as they used alternative sources that were inextricably linked to their cultures, contexts, and, communities.

#### RESEARCH DESIGN AND METHODOLOGY

An ethnographic approach was used to study the women's experiences of health and their learning inside and outside of a literacy programme in a local community (Barton & Hamilton, 1998). This approach revealed rich information about the women's reading, and its connection to their health, with their frames of references and values, all, in the context of rapid social change.

## Data Collection (Techniques)

I used a Hawaii-based interviewing technique, called, 'talk story' to hear the women's stories in their first language, from their viewpoints, and in an open-ended way. Talk story is a favored communication form among local people in Hawai'i, and other researchers have used this technique to get the 'insider perspective' (Briggs, 1996; Taosaka 2002, Lebra 1991, Kneubuhl 1996, Salice 1991). I lived in Hawai'i for three

years prior to the study, and understood Hawai'i Creole English and how to use talk story. Talk story encompasses loosely structured interviews with local people that allow for their stories to emerge about everyday topics like food, health, and work. I explored these topics in my interviews with the learners and also talked to the their tutors and the staff about what they knew about the women's lives and learning. Additional interviews with community literacy educators and social service counselors expanded my perspectives on the ways institutions had recently changed and became more textualised, or paper-based (Barton & Hamilton, 2005).

I conducted five life history interviews with each women over a period of a year. These interviews focused on many different aspects of their lives, including their education and work histories, about their learning and communication in their families, and the mass media they used in their daily lives. The women were also observed outside of the program, which included going to church and attending other community events with them. Inside the programme, I examined their work folders, and observed them learning with their tutors, in small groups, and by themselves. Documentary analysis of literacy program materials, community historical records, and environmental and community print, in conjunction with photography supplemented the interviews. Finally, I immersed myself in the community for two years as a teacher and community member, and lived with a local family, all of which were indispensable for learning about how texts fit into the women's way of life.

Data collection (Respondents)

Gloria was a Hawaiian women, a widow, in her early 50s who grew up on the island and had dyslexia and a severe case of asthma. When she learned that her welfare would be cut off (because her doctor would not claim she had dyslexia), she started attending the learning programme in order to raise her literacy skills enough to apply for, and keep a job. She struggled to read texts in the programme that she had never before encountered in her work life on pineapple, macademia and coffee plantations and factories, in caring for family members, or in her social life, where she sang and volunteered at church. Although she was classified at an entry level of literacy, she read popular religious materials at a much higher level, because she considered them to be therapeutic and knowledgeable.

Lourdes, also in her early 50s, and originally from Mexico, lived in Hawai'i for over 20 years, was married to a local Hawaiian man, and raised her children there. While she had many jobs in her past, including papaya grading and sewing aloha shirts, she was currently a therapeutic aide in a nursing home. The company recently merged with another one, and with her new position, she was expected to submit weekly reports of her activities. She attended the learning programme in order to improve her writing skills in order to meet these work demands. In addition to having to write these difficult texts, she also struggled to read her doctor's reports, and experienced great distrust of the system, due to consenting to a hysterectomy that she later discovered was unnecessary. She had some depression related to this, and her menopause, and she relied on a slew of popular religious and self-help texts that were at much higher levels than her classification in the program (an ESOL level 2). Like Gloria, she used both print and electronic sources. She watched a nun on television who comforted her and reminded her fondly of her girlhood

days in Mexico. She also attended church, and like, Gloria, would be considered deeply religious, often praying by herself, and, referring to many daily problems as God's will.

Data Analysis

I used a narrative analysis technique to capture the women's unique stories about health, and then profiles were created from these narratives, which are presented in this article. The narrative approach (Gluck and Patai 1991, Riessman 1993, Witherell & Noddings 1990) complemented the talk story method, and lent the women voices to 'story' their uses of texts for healing. The narrative analysis also highlighted the women's decision-making, and their evaluations about their health problems in the context of their daily lives.

The narratives were then formulated into profiles of their vernacular texts for healing in the context of Hawai'i. Profiles (Seidman 1991) offer opportunities to see nuanced processes and how events unfold under special circumstances, in this case, two women and their uses of health texts. I also cross-compared the individual profiles to unearth major themes, one of which was the social literacy practices of health and healing (to be discussed in the findings section).

A PROFILE OF LOURDES: 'AND I REMEMBER FEELING VERY UNCOMFORTABLE ON THAT'

Although Lourdes had a hysterectomy, she was surprised at having menopausal symptoms, 'I didn't know it was that. Cause for one thing I had a hysterectomy. So I didn't

expect so much changes. I used to feel real lonely like. Real lonely you know. Nothing. Everything was the same. It's just the feeling in your head.' She recalled how she felt about her changing body, which led her to get a book from the library, called, *The Silent* Passage, mentioned by a co-worker. She said, 'Well for instance, I didn't know any symptoms. Nobody ever told me what you're gonna feel. Like now. I finished. I finished yea and I didn't know anything. I was what, forty-four year old and I was going crazy you know. You feel like you're going crazy. And I didn't know what's going on. Somebody told me, go to the library and get a book.' Although this book would be considered far above her programme level, she read it, and even transmitted this information to other women co-workers. She recalled, 'and then we start talking and then we find out we have the same feeling.' In many respects, Lourdes took care of her needs by giving voice to this 'silent passage' and passed on the knowledge to other women who exhibited similar symptoms. She also informed herself of her Premarin medication, which her doctor didn't tell her about, through the help of a pharmacist who noticed that she was anxious. She recalled: 'He said, oh you're so . . you look very anxious. Anxiety or you know--I couldn't sit still. Or, and then I told him what is this for? And then he told me what the Premarin for. It's a hormone. And then he gave me the paper. A long paper like this. He said read this. I didn't know what I was taking.' Lourdes trusted the doctor who gave her the prescription, and she took the medicine without knowing what it was for six months. She remembered, 'Cause when I went to the doctor, he didn't tell me. He gave me the Premarin and he said take this and you feel better. And I remember feeling very uncomfortable on that. I didn't ask him why. Or nothing. I just thought, well you're the doctor. You're supposed to know better.' After the pharmacist explained the purpose of the medication and its side-effects, she told the doctor, 'I don't need this.' She then began

taking vitamins instead of hormonal supplements because she believed they were 'good.'

The meanings of her health care and how she managed it through power struggles, informal advocates, reading for meaning, critical questioning, alternative health supplements, prayer, and conferencing are not captured in the functional health literacy literature. Neither are the ways she knew her symptoms through experiential knowledge as opposed to literacy discourses and formalised instructions by doctors.

Lourdes said, 'not forget, forgive' about this traumatic experience. This metaphor, of forgiving but not forgetting, reflected her sacred beliefs and cultural knowledge that she drew on in her decisions about her health and as it intertwined with power relations, spirituality, self-care, and emotions in her daily life. The selfimprovement and spiritual readings that she used healed her in ways totally different from the health work she did in her health aide position, or, in the reading involved in taking pills. She used this literature for comfort, for self-assertion, and healing as well as being an authority to co-workers about menopause. She often read the Bible at all hours of the day, and she regularly read, 'pick me up prayer' books too. She said, 'Pick me up, and it's like if I do a lot of things for somebody, then something goes wrong, I remember what that book says.' In addition, she listened to biblical tapes which helped reinforce her faith, and belief that 'God was watching over' her. Rodriguez (1994) studied the ways Mexican-American women develop their strength and heal themselves and others through strong female imagery. The provocative image of the nun Lourdes watched every night on TV referenced 'Our Lady of Guadalupe' for the comfort, devotion and inspiration which infused her work and home relations. The readings supported these purposes too:

So I pray and pray and then it's like somebody just open the door . . . . yea it's better than fighting . . . try to forget I guess. Forgive and forget . . . . yea, because that's what I forgive. Takes time, but it's possible. Not forget, forgive. You know before I go to bed I listen every night to channel 19. I don't know if you get the channel. A religious channel. It's a Catholic channel. They have this nun. Mother Angelica. It on at 10 every night--- I listen to her. Because she talks about God. People call in with problems and she tell them what to do or where to go.

This mantra was constantly reinforced through her mass media practices, which reconnected her to her inner self and her past life--propelling her to the next stage of learning. The self-improvement books she bought and borrowed, and heard from the TV celebrity, Oprah and a nun reinforced the cultural knowledge that she obtained in her formative years in Mexico with her evangelical family.

Her knowledge about healing, transformation and inspirational figures clashed with her negative experience of a doctor who quickly diagnosed her, showed her a picture of a uterine tumor, had her sign papers, and gave her a hysterectomy. She recalls, 'So he set everything up quick. I sign the paper and I went surgery. Said oh boy. But now I'm older and wiser....I wouldn't have. I would never have surgery.' She knew that by asking for alternative help, even reading magazines, and through television, she could get information that would help her in the future. This experience made her distrust the doctor's judgement and left her distrustful of the system in later encounters with doctors.

Eventually, she chose not to reject something that she saw as a natural occurrence, 'it's a natural thing to happen to every woman. Why fight it? Just let it go.' These sources gave her a sense of control that she had previously lost.

It could be argued that Lourdes' lack of faith in the health care system made her cynical and entrenched her faith in alternative healing. For example, at work, she was devoted to patients, and said 'I love old people,' but she constantly had to 'pass meds and boss people around.' She also had to 'say something on paper' every week and report on her patients as if she was studying, rather than caring, for them. She relied on her prayer books and other self-help literature for self-assertiveness at work, and to be in touch with her needs and emotions to care for herself and for others. She said, 'the first book I read-I'll never forget it. Was back in 19, maybe 1981, was with Norman Vincent Peale, the positive thinking. Oh that book was good. So from then on I start, you know, in my head I can do it.' These books helped made her feel independent, go back to work and not, 'listen to my husband too much. I have my own mind, why should I listen to him?' She also used these books to assert herself on the job. Lourdes used these popular texts as replacements for institutional measures.

# A PROFILE OF GLORIA: 'WITH WISDOM AND KNOWLEDGE, THERE'S GREAT SORROW'

Gloria discussed how she came to terms with adult onset-asthma: 'Cause, you know, with wisdom and knowledge, there's great sorrow. That's in the Bible. With wisdom and knowledge. Because you see the person and they're screaming, and you

know how to get them out of the situation ...It took me a whole year to settle down. It took me another year to say yes, it is [asthma]. And then this year I finally said, OK, I admit it, and now I know.' Gloria received factual information from her doctor about asthma, which she then interpreted it into something she related to, like, biblical teachings, eating correctly, and acknowledging she was ill—something that was not part of her identity, as she had previously been very healthy. She interpreted the doctor's advice to fit with her own knowledge system: 'So its like, OK, now, say I've got a problem with my health. Which I had. Because it's reality. Everybody don't want freezer food. They want facts... So, it's in my body system. And then the second thing is, 'What you put in is what you get out.' So if I put in like, negative words, negative come out. If I put good food in, good food—your body will function.'

Turning to the Bible, in print and electronic forms (tapes and software), allowed her to be in touch with her body's signs and depend more on herself, 'I put the Bible tapes on cause when I couldn't read, then I usually trust everyone.' She went on to discuss the importance of biblical values of moderation for dealing with the asthma. This was taught to her through an icon of a bumblebee devouring honey on her Bible software programme. Tuning into her symptoms, and learning about them, was critical to her health care. She said, 'I didn't know how to be sick. I have to learn the symptoms.' For Gloria, learning the symptoms meant recognising her emotional states: 'With wisdom and knowledge, there's great sorrow' she said.

Gloria also knew about using her mental and spiritual powers of healing through her experience of caring for family members. Taking care of her ill mother and husband gave her a strong sense self. But it was much work. She recalled, 'cause he [her husband] was going to die pretty soon, eventually and my mom was dying of cancer. So, that's work cause you have to discipline your mind to be strong.' Gloria viewed taking care of her own body as work. She had to chart her breathing and deal with the side effects of the medicine which didn't feel natural to her self-image. She described her asthma as a, 'monster' especially when the doctor was not following up on her self- reports of her symptoms. She said, 'I still don't feel well and I told my doctor that, so we haven't really looked into it. And I haven't really pursue[d] it, cause I wasn't ready to face anything else....so now that I'm a little strong to face the monster, I'm not afraid now, so when I have to talk it, that's work.'

Gloria was scared about how to handle her asthma. It felt out of control and the doctor was not alleviating it. Her constant battle around the steroids that he gave her, and whether or not it was really helping, made her feel like caring for herself was emotional work because her 'body lets me know who is boss' and the doctor was not 'God; 'What's more, the doctors depended on her to name the symptoms, which created more stress because they were hard to articulate. She explains:

I [am] trying to get this asthma thing under control. And one minute, it seems like it is under control and then all of a sudden it flares up again.... But I thought I'd try to go on 5 miligrams of that steroid. And every time I kind of take one step lower, my body lets me know who is boss and it's it. It won't listen to me even though how much I beat it up.... and it takes a lot of work just to keep healthy. It takes a lot of work to stay still. Keep yourself calm. Talk to yourself, relax. Even

if your body will not pay attention. So that's' work. That's a lot of work, especially emotional, cause you taking the medication and it's not listening. And it's not the doctor's fault. It's learning what your body can handle and what it can not handle. And that's what I told my doctor. I said, he's not God.

Gloria attempted to heal herself and pay more attention to her emotional states, which was critical her health care. This was especially the case because feeling anxious triggered her asthma episodes. Part of her healing encompassed trusting a higher force (a God) which calmed her down and gave her a feeling of control and relaxation. Her books became 'a study tool' which was solacing. She said: 'This is what the pastor said, when you're reading, it's like a love letter....So the Bible is actually a love letter. And he [is] telling you what's taking place in the world.'

Coming to the literacy programme was difficult for Gloria because the dust and mold in the building aggravated her condition, and it was exacerbated by the stress of her case worker pressuring her to raise her skills quickly in order to find a job. It didn't help that she discovered, upon entering the programme, that she was at an entry level of literacy and it would take much longer to achieve the case worker's goals. It also didn't help that she felt she had a disability, dyslexia, which no one seemed to acknowledge or address seriously. The fact that her doctor denied, on paper, that she was not dyslexic and could engage in paid work (instead of just receiving welfare) demoralised her. She used food to comfort her when she felt pressured and sick, but this strategy was to no avail.

Taking care of herself felt like a daunting task in light of all of the demands placed upon

her. While poi, a Hawaiian food, was normally what she liked to eat to comfort herself, she tried to relax with other food instead one night. She recalled:

I started to cry. And I didn't cry, oh gosh I'm only in the 4th grade level [of literacy]. Then I thought, I have to go to work. They pushing me there, the welfare people. They said they got to hunt for work and I'm not well. And I have to go to work. How am [I] gonna work this out....Like you don't know what is sick. I thought, maybe if I had sardine and wine. I love sardine. And I'll eat it away. I'll eat my food and this sickness will go away. So at 11 at night I'm eating my food-relax Gloria, its only in your mind. You need your job. Welfare [is] not going to help you. Got to get going now girl. So I end up in the hospital for a week and I was laid up for a whole month.... So that was very hard, you know. And it's still really hard. And I'm not told, disability. I have one disability. And right this very minute I feel pressured to go to work.

Under these circumstances, of having few economic resources, pressures to work and learn in a literacy programme, exacerbated by little help from her doctor and all of those around her, she felt her body and life were out of control. Viewing her body as part of a congregation or 'church' allowed her to re-attach herself to the world in a safe, trusting way which was sanctified by spiritual purposes, and connected her to a supportive community of people.

#### **FINDINGS**

Health care arose in formidable ways in Gloria and Lourdes' stories, representing many of the women's stories and highlighting it as a major theme in my research. The women had health problems that included asthma, back pain, cancer, thyroid problems, depression, and, they also cared for ill family members. The women told the researcher about how doctors advised them through print formats, brief oral consultations, pills, and surgeries. Yet, they often turned regularly to biblical teachings, spiritual counselors, prayer, and other alternative therapies. Their engagement with these sources allowed them to become attuned to their symptoms, learn about their bodies, and manage their illnesses, in the best ways they could. Yet these opposing health discourses were in conflict for the women as they struggled to improve their health care and learn literacy but with little help from the experts to whom they initially turned.

Gloria, for example often turned to poi (a Hawaiian staple), other local foods, and herbs to cope with her asthma condition, as well as reading the Bible. She did this because she saw her body and her spirituality as inseparable. She said, 'I always say one building is the lungs. One building is the heart. One building is the liver. . I am in this church right this very minute....and if we all come together, we need each other. Cause we make partner, the body.' These rituals were supported by her community, but were not responses that her doctor understood or supported.

Like Gloria and Lourdes, other women learners who were interviewed trusted popular culture materials for their health care. There was Margaret, who used Jehovah Witness magazines as alternative sources for health-related concerns. Another learner, Rosalia, read fitness magazines and power walked with a co-worker. There were many

other examples of women who embraced alternative health modalities and vernacular texts for dealing with their health problems. These women's alternative responses to their health, and their literacy uses, contradicted the conventional biomedical literature they were given in health care facilities, which focused on knowing medical facts, as well as the literacy programme library which held a small amount of conventional health care information. This literature was meant for individual use. Yet neither of the women navigated their problems alone. Instead, both women used mediators, or, sponsors to learn about their health (Brandt, 2001; Cuban, 2003). Gloria was close to her minister and his wife, to other congregation members, and she also had a 'spirit man' who guided her along her therapeutic journey. Lourdes watched a Catholic nun on TV, and read her religious and new-age self-help books and shared them with others. They both used these sacred materials to work on their emotional problems that were related to their physical conditions, and viewed these activities as health promoting. These sources also compensated for the gaps left by their doctors (who requested their patients to fill in forms rather than spending the time to listen and deeply understand their problems).

The women saw their bodies, feelings and spiritual needs as integrated with their health, and not discrete and mechanised. Gloria, for example, called, it, 'a body system' of 'knowledge and wisdom.' These popular sources were catalysts for the women in coping with their problems, but more importantly, for viewing their life experiences and personal development. This type of reading seemed to bring the women closer to knowing and learning about their symptoms, especially when they were validated by other authorities in their communities. This issue is critical in practical ways, because if doctors depend on women to describe their symptoms accurately, it is essential that women be

sensitised to their bodies and emotions. These reading sources reinforced their experiential knowledge of their problems, and, in a sense, became diagnostic tools to understand their health (Polanyi 1998, Rapp 1997).

# PRACTICAL AND THEORETICAL IMPLICATIONS FOR HEALTH LITERACIES

### Practical Implications

Reading for emotional purposes not for pre-processed facts, may be more beneficial in diagnosis and treatment, especially in the case of certain problems. The functional health literacy formula of upgrading literacy learners' skills so they can read health care texts, or, turning all health care texts into Plain Language (easily readable), are only superficial solutions for the complex problems of women like Gloria and Lourdes. Literacy programmes can encourage learners to discuss their health problems in a safe environment rather than simply recording these in a log as barriers to attendance. These discussions can be in the form of learning circles, where there is no head of the table, and everyone takes turns sharing their issues and forming networks to offer support that extend beyond the literacy programme and into the community.

Yet, learning circles go beyond just offering emotional support, and they have social value too. They offer learners the opportunities to be advocates and community health leaders. People collectively engage with, analyse, and seek solutions, using and developing community resources. Lyn Tett (2003) studied a health community course of women learners who took collective action to change conditions in their community to produce greater health outcomes. One of these was housing. Working together, the

women began to see that their housing and health issues were not isolated incidences or private issues, and that were connected to each other. Through advocating collectively, they campaigned for, and got, better housing amenities.

Conferencing strategies (between learners and staff or tutors and learners or learners with one another) offer focused opportunities to share information and develop solutions to problems. It also gives staff and tutors opportunities to understand how learners understand and make decisions about their bodies, what sources they use, especially other community members they consult with, acknowledges a collective view of health care (Fadiman 1997, O'Connor 1995). These long dialogues can occur in intake sessions where there are opportunities to advise and gain information on both sides. Much of this can be gathered by learning about women's life stories and creating narratives of their experiences.

Once this information is known, the curriculum can address learners' health experiences, their vernacular health practices, and the health mediators they use in their communities. Using an engaged curriculum (Boudin 1983, hooks1994, Hohn 1997) incorporates women's experiences and expressiveness, aiming for an education that is socially transformative. This health literacies curriculum addresses women's collective senses and interpersonal reasoning around health care (Witherell and Noddings 1990) that may be beneficial in naming and treating problems holistically.

Finally, without acknowledging the importance of health literacy policies, changes cannot occur. Currently, government policies support the functional health literacy

paradigm described above (Rudd, 2002), rather than the social practice perspective. The basic skills agendas of most industrialized countries' adult basic education systems is functional, with a focus on knowing mainstream vocabulary in order to pass tests. Also, current funding structures support the spread of functional health literacy in adult basic education; Pfizer, for example, is a major supplier of health literacy grants. Another mechanism for the influence of functional health literacy are the many regulations in health care facilities that produce massive amounts of paperwork for patients to read, making the case for FHL advocates to teach functional health literacy in programmes. Greater policy interventions are needed to insure wider access, support structures, and opportunities for health literacies (from people's communities) to flourish.

## Theoretical Implications

The mainstream health clinics where the women went for their health care compartmentalised their health problems and did not recognise the standards they used to perceive their health, their native ways of knowing (Bouscouvalas, 1993) nor their 'lifeworld systems' (Welton 1993). This phenomenon was largely due to cultural and social class discrimination. But it was also related to gender discrimination, and the dismissal of women's "embodied accounts of the truth" (Haraway, 1991 p. 186). The insider's perspectives, according to Donna Haraway, should be distinguished from expert stances. As women tell their stories, their local knowledges and "webbed accounts" (Haraway, p. 194) are highlighted through their power relations, bodies, habits, and material circumstances (Hartsock, 1987; Lamphere, Ragone, & Zavella, 1997; Sachs, 1996). Yet these knowledges are invisible within the mainstream medical establishment. Furthermore, women are given few opportunities to confront the medical establishment as

part of their healing and transformational development (Brooks, 2000). For this reason, it would be important to expand the critical vernacular framework to generate a broader range of explanations about marginalised women's health literacy practices and experiences.

### CONCLUSION

To summarise, the women's acceptance of alternative modalities, like these popular texts, were mediated by their ethnic backgrounds, gender, and generation (Sachs, 1996), and was carried into the present in a semi-rural area that lacked medical options, in conjunction with increased managed care, and during an era of welfare reform. The legendary missionary heritage that was imprinted and transmitted by the many small churches, through local culture, also influenced their practices.

The women's ingenious practices offered a window into the cultural, community-based strategies they used to heal themselves which were not supported by the programme they attended nor the services to which they initially turned to for help. Yet they did obtain alternative resources in their communities to help them cope with their health problems and they strategically used them. As the study demonstrated, little cross-over existed between the local community and its institutions, and more mediators of literacy were needed by the women to bridge these gaps and provide diverse resources. Moreover, as the women's stories suggest, learners need more than bridges, but, advocates for their greater self-determination and educational aspirations. They need to see both social and educational systems (health care facilities and literacy programmes) as allied with them, rather than as distant authorities; as Gloria stated, 'us the body' and

'we make partner, the body.' Through these connections, communities can transform themselves into "therapeutic landscapes" (Gesler, 1992) that foster dynamic, holistic ways that people use literacy and seek information for healing.

#### REFERENCES

- Adams, D. L. (Ed.). (1995). *Health issues for women of color: A cultural diversity perspective*. Thousand Oaks, CA: Sage.
- Barton, D. and Hamilton, M. (1998) Local Literacies: A Study of Reading and Writing in One Community Routledge.
- Barton, D. & Hamilton, M.(2005). Literacy, reification, and the dynamics of social interaction (14-35). In D. Barton & K. Tusting, *Beyond communities of practice: Language, power, and social context.* Cambridge: Cambridge University Press.
- Berg, S. (1989). *Bridges to Literacy: Today's plan for tomorrow's Hawai'i*. Honolulu, HI:

  Hawai'i's Literacy Assessment Report and Statewide Plan, Office of Children and Youth,

  The Governor's Council for Literacy.
- Bloor, M. (2001) The ethnography of health and medicine. In: Atkinson, P.Coffey, A., Delamont, S., Lofland, J., Lofland, L. (eds) Handbook of Ethnography. London: Sage, pp. 177–187.
- Boucouvalas, M (1993). Consciousness and learning: new and renewed approaches. In S. Merriam (Ed.), *An update on adult learning theory. New directions for adult and continuing education, no.* 57 (pp. 57-69). San Francisco: Jossey-Bass.
- Boudin, Kathy (1983). Participatory literacy education behind bars: AIDS opens the door. *Harvard Educational Review*, 63 (2) 207-32.

- Brandt, D. (2001). Literacy in American lives. New York: Cambridge University Press.
- Brooks, A. (2000). Transformation. In E. Hayes & D. Flannery with A. Brooks, E. Tisdell, & J. Hugo. *Women as learners : the significance of gender in adult learning* (pp.139-154) .

  San Francisco : Jossey-Bass Publishers.
- Courtenay, B., Merriam, S., Reeves, P., & Baumgartner, L. (2000). Perspective transformation over time: a two year follow-up study of HIV positive adults. *Adult Education Quarterly*. 50 (2), 102-147.
- Cuban, S. (2003). 'So lucky to be like that, somebody care': Two case studies of women learners and their persistence in a Hawai'i literacy program. *Adult Basic Education*, *13*(1), 19-44.
- County of Hawai'i. County of Hawaii Data Book. (1996-1998). Hilo, HI: County of Hawai'i, Department of Research and Development.
- Davis, S.P. & Ingram, C.A. (1993). Empowered caretakers.. In B. Blair & S. Cayleff (Eds.),

  Wings of gauze: women of color and the experience of health and illness (pp. 191-201).

  Detroit: Wayne State University Press
- Doak, C., Doak L., & Root, J. (1996). *Teaching patients with low literacy skills*. PA: Lippincott Co.
- Fadiman, A. (1997). *The spirit catches you and you fall down*. NY: Farrar, Straus & Giroux. Fairclough, N. (2000). New labour, new language? London: Routledge.

- Fitzsimmons, K.A. (1991). African-American women who persist in literacy programs. *The Urban Review* 23 (4). 231-250.
- Field, J.(2006). Lifelong learning and the new educational order. Sterling: Trentham Books.
- Gesler, W. (1992) 'Therapeutic Landscapes: Medical issues in light of the new cultural geography' *Social Science & Medicine* 34(7): 735-746
- Gluck, S., & Patai, D. (Eds). (1991). Women's words: the feminist practice of oral history. New York: Routledge.
- Greenberg, D. (2001). A critical look at health literacy. Adult Basic Education, 11 (2), 67-79.
- Haraway, D. (1991). Simians, cyborgs, and women. New York: Routledge.
- Hartsock, N. (1987). The feminist standpoint. In S. Harding (Ed.), *Feminist methodology*. (pp. 157-177). Bloomington: Open University Press.
- Hohn, M. (1997). Empowerment health education in adult literacy. Washington, D.C.: National Institute for Literacy.
- hooks, b. (1994). Teaching to transgress. NY: Routledge.
- Hull, G., Mikulecky, L. St. Clair, R.. and Kerka, S. (2003). Multiple Literacies: A Compilation for Adult Educators (ACVE, 2003).
- Isaac, E.P., Guy, T., & Valentine, T. (2001). Understanding African-American learners' motivations to learn in church-based adult education. *Adult Education Quarterly*, 52 (1): 23-38.
- Jacobsen, W. (1996). Learning, culture, and learning culture. *Adult Education Quarterly*, 47 (1), 15-28.
- Kana'iaupuni, S.M. (2004). Ka'akalai Ku Kanaka: A call for strengths-based approached from a Native Hawaiian perspective. Educational Researcher, 33 (4), 26-32.

- Kelly, M., Nakamura, B., & Barrerre, D. (1981). *Hilo Bay: A chronological history: land and water use in the Hilo Bay Area, Island of Hawai'i.* Honolulu: Bishop Museum.
- Kerka, S. (2002). Somatic/Embodied Knowing. ERIC Trends and Issues.
- Lakes, R.D., & Lewis, L.H. (1990). Literacy and the black church: a demonstration project in Conneticut. *Adult Literacy and Basic Education*, 14 (2), 65-75.
- Lamphere, H., Ragone E, & Zavella, P. (Eds.) (1997). Situated lives: gender and culture in everyday life. New York: Routledge.
- Lave, J., & Wenger, E. (1991). Situated learning: legitimate peripheral participation. NY:

  Cambridge University Press.
- Meyer, M. (1998). *Native Hawaiian epistemology*. Unpublished doctoral dissertation.

  Cambridge, MA: Harvard University.
- Moss, B. (Ed.). (1994). Literacy across communities. Creskill, NJ: Hampton Press.
- Nutbeam, D. (1999). Literacies across the lifespan: Health Literacy. *Journal of Literacy & Numeracy Studies* 9 (2), 47-55.
- O'Connor, B. (1995). *Healing traditions*. Philadelphia: University of Pennsylvania Press.
- Omnitrak Research and Marketing Group. (1989) <u>Hawai'i Statewide Literacy Assessment</u>
  (HSLA). Honolulu, HI: The Group.
- Papen, U. (2005). Adult literacy as social practice: More than skills. New York and London: Routledge.
- Papen, U. (2006). "Health and Literacy." Presentation at Lancaster University, May 13, 2006.
- Payer, L. (1988). Medicine and culture. NY: Henry Holt & Co.
- Polanyi, M. (1998). Personal knowledge. London: Routledge
- Rapp, R. (1997). Constructing amniocentesis: maternal and medical discourses. In H. Lamphere,

- Riessman, C.K. (1993). Narrative analysis. Newbury Park, CA: Sage.
- Robinson-Pant, A. (Ed.) (2004) Women, Literacy and Development: alternative perspectives, Routledge: London.
- Rodriguez, J. (1994). Our lady of Guadelupe. Austin: University of Texas.
- Rowland, M. (2000). African-Americans and self-help education: the missing link in adult education no. 222. Columbus, OH: ERIC Clearinghouse for Adult, Career, and Vocational Education, Ohio State University.
- Rudd, R. (2002). A maturing partnership. Focus on Basics. 5, C, 1-10.
- Sachs, C. (1996). Gendered Fields: Rural women, agriculture and environment. New York: Westview Press.
- Salice, B. (1991). Palapala: Language, literacy and learning among native Hawaiian women in Waimanalo, Hawai'i. Unpublished doctoral dissertation, University of Southern California, San Diego.
- Seidman, I.E. (1991). Interviewing as qualitative research: A guide for researchers in education and social sciences. New York: Teacher's College Press.
- Selden, Catherine; Zorn, Marcia; Ratzan, Scott C.; Parker, Ruth M., compilers. (2000).

  Health literacy. Bethesda (MD): National Library of Medicine. Available from:

  http://www.nlm.nih.gov/pubs/resources.html
- Shohet, L. (2004). Health and literacy: Perspectives. *Literacy & Numeracy Studies* 13 (1), p 65-84.
- Tanner, C. Benner, P., Chesla, C., & Gordon, D. (1996). The phenomenology of knowing the patient. In S. Gordon, P. Benner, & N. Noddings, N. *Caregiving: readings in knowledge*,

*practice, ethics, and politics* (pp. 203-219). Philadelphia: University of Pennsylvania Press.

Tett, L. (2003). [Health] Paper from the Adult Education Research Conference, San Francisco State University, San Francisco.

Tomlinson, S. (2005). Education in a post-welfare society. London: Open University Press.

Waerness, K. (1996). The rationality of caring. In, S. Gordon, P. Benner, & N. Noddings (Eds.), *Caregiving: Readings in knowledge, practice, ethics, and politics* (pp. 231-254).

Philadelphia: University of Pennsylvania Press.

Ward, M.C. (1999). A world full of women. Needham, MA: Allyn & Bacon.

- Welton, M. (1993). The contribution of critical theory to our understanding of adult learning. In S. Merriam (Ed). *An update on adult learning theory* 57 (pp. 81-90). San Francisco: Jossey-Bass.
- Wilson, A. (1993) The promise of situated cognition. In S. Merriam (Ed.). *An update on adult learning theory. New directions for adult and continuing education, no. 57*, (pp. 71-79). San Francisco: Jossey-Bass Pub.

Witherell, C., & Noddings, N. (1990). Stories lives tell. New York, Teachers College.