

# Uncertainty amidst routineness

## *How three lung cancer patients experienced alienation in biomedical institutions and personal relationships*

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*Anthropological and clinical research has brought to light emotionally isolating effects of receiving biomedical treatment for serious illnesses such as lung cancer. This essay illustrates how these isolating effects can manifest for individuals by presenting the experiences of three lung cancer patients in England who were interviewed between 2000 and 2003. The patients discussed feeling emotionally alienated in medical contexts because their illnesses tended to be routinely encountered by their caregivers, yet new and frightening for themselves. They stressed the importance of meaningful relationships with individual care providers in mitigating these alienating effects. They also discussed tensions between the emotional support provided by family and friends, and difficulty when the same loved ones could not fully understand their illness experiences. I conclude that in biomedical institutions and society as a whole, greater attention should be paid to patients' feelings of isolation and alienation, and that the root causes of these experiences should be examined at institutional and societal levels.*

## Introduction

This essay, meant to highlight ideas rather than present research findings, closely examines narratives of three lung cancer patients in England, with the pseudonyms Susan, Stanley, and Roger, interviewed between 2000 and 2003 by the Health Experiences Research Group (HERG) at Oxford University, as part of a qualitative study on lung cancer patient perspectives. All patients received lung cancer diagnoses and care through England's National Health Service (NHS England) between 1999 and 2003. In semi-structured interviews in their homes with researchers from HERG, patients were asked to describe their experiences of lung cancer and treatment. The interview transcripts were given to the author of this essay in order to extract analytical themes that would promote understanding of patient experiences with lung cancer. This essay focuses on patient experiences of isolation and alienation in biomedical institutions and personal relationships.

In order to receive treatment, Susan, Stanley, and Roger submitted themselves to the biomedical system and experienced emotional alienation within biomedical and personal social worlds. They voiced feelings of aloneness resulting from uncertainties and ambiguities arising during medical treatment and discomfort from the "self" being treated as a sort of nuisance by medical institutions. They described the uncomfortable alienation of feeling personally uncertain, afraid and in new territory, yet becoming the routine, even mundane object of the doctors' work. They described the humanizing role of family and friends, but also isolation due to loved ones' distance and difficulty understanding their illness and treatment experiences.

This essay selectively reviews classical medical anthropological literature on patient-centered research that concerns alienation in biomedical and broader social contexts. After the literature review, the perspectives of the three patients are presented in two sections. The first section deals with patient experiences of isolation in medical institutions, while the second section analyzes experiences of emotional support and alienation from family and friends.

## Literature review

Anthropological research on biomedicine voices patient perspectives of medical encounters and describes biomedicine as a cultural, historical construct. It reveals sociocultural particularities of biomedicine obscured by the illusion of objective,

rational and natural reality — or a so-called “aura of factuality” (Geertz 1973, Rhodes 1996). Uncertainty and discomfort arise for patients facing culturally-specific models of illness and healing considered acultural by biomedical discourse.

Medical anthropologists have long described biomedicine as a socioculturally-embedded site of social control, reflective and reproductive of broader social priorities such as depersonalized capitalist efficiency, power-reinforcing hierarchy, commodification of bodies, neoliberal individualism, alienation of body and mind etc. (Foucault 1975, Baer et. al 1986, Martin 1987, Scheper-Hughes and Lock 1987, Kleinmann 1988). Others have depicted the biomedical clinic as a culturally unique space that breaks otherwise ubiquitous norms — for example, giving a near-stranger (a doctor) unprecedented physical access and knowledge of one’s body — and requires re-socialization for its participants (healers and patients) to accept unique social rules (Taussig 1980, Konner 1987, Good 1993). Biomedicine as a system of knowledge and practice thus has a special role of both breaking and reinforcing social codes. Biomedicine is a socially distinct structure that presents itself as natural and consistent with the rest of society, by way of justification through scientific rationality and mirroring of other societal power structures — creating ambiguities and confusion for the seriously sick seeking biomedical care.

This is not to strictly distinguish biomedicine as confined to the clinic, or to depict it as a distinctly bordered institution ready for the sick to enter — on the contrary, biomedicine’s explanatory models pervade everyday consciousness in the Western world. As Baer et al. (1986) write, “*the dominant ideological and social patterns in medical care are intimately related to hegemonic ideologies and patterns outside of medicine*”(95). This makes it difficult to epistemologically disentangle the biomedical domain from the rest of society. Rather than consider biomedicine as an “intervention” that imposes on sickness and life, this essay, and the patients interviewed for it, more closely describe a model of entrance into biomedical care as a culture and social hierarchy.

One effect of a distinct biomedical culture is that it can leave patients feeling isolated from the biomedical social world. This essay extends anthropological ideas of biomedicine as a unique culture and social structure to account for the fact that patients are typically newer to the biomedical social world than physicians and can feel like outsiders or alone in their illness experiences. They struggle to deal with the asymmetry of their illnesses as routine to medical professionals, but new, frightening, and uncertain to themselves.

Linked to isolation in the biomedical realm is the alienation patients can feel from loved ones and society while undergoing biomedical treatment. Medical

anthropologists have commented on the emotional importance of social support networks during medical illness (Cohen 1988) and on social stigma of illness, particularly cancer (Sontag 1978, Cataldo et al. 2011, Marlow et al. 2015). This essay applies these authors' ideas to examine how patients' loved ones help lessen feelings of isolation arising from biomedical explanatory models, and examines how patients struggle to relate to loved ones who cannot fully understand their experiences in the biomedical institution.

Close examination of patient experiences can bring into relief the isolating effects of biomedical treatment. Due to recognition of the harm that results from disconnects between biomedical and patient perspectives (Fadiman 1997), biomedical discourse in the past decade has emphasized responsiveness to patient "explanatory models" of illness and healing (Kleinmann 1988) through "cultural sensitivity" (Loue et al 2015), "cultural competence" (Shaya et al. 2006), "patient-professional partnership" (Powell 2013), "person-centered care" (Herlitz et al. 2016), "shared decision making" (Herlitz et al. 2016) and other measures meant to break down paternalistic models of care and fully address the social dimensions of health and illness with the goal of improving health outcomes. These objectives require deep understanding of patient experiences — gathered from close analysis of patient narratives — in order to address alienation from practitioners and personal relationships experienced by patients dealing with illness in the context of both biomedical institutions and their broader social, cultural, political environments (Kleinmann 1988).

## The interviewed patients

Susan, at the time of her interview, was a 55 year-old educational administrator, divorced with two children. She was diagnosed with non-small cell lung cancer in 2002 and received chemotherapy treatment and lobectomy (lobe removal) surgery of the lung. Months later, metastases were found in her brain. She received radiotherapy, and died in 2003.

Stanley was a 66 year-old retired excavator driver at the time of his interview, married with four children. He was diagnosed with lung cancer in 1999 after two heart attacks prompted doctors to take a chest x-ray. He had a lobectomy in 2002, but cancer was later found to have recurred in his lymph nodes. After chemotherapy and radiotherapy he died in 2003.

Roger was a 62 year-old company-manager at the time of his interview, married with three children. In 2002 doctors found fluid in his lungs, and after an operation to remove the fluid, a biopsy showed mesothelioma, a type of lung cancer most commonly associated with exposure to asbestos. He received chemotherapy through a clinical trial, and at the time of the interview, conducted directly after his 6-month course of treatment, his tumors had shrunk dramatically and he awaited further evaluation.

## Alienation in medical institutions

### *The patient as an “epiphenomenon”*

Patients felt alienated from biomedical social structures and explanatory models that were new to them, but not to health practitioners. This made patients feel like their jarring illness experiences were often routinized and dismissed by caregivers. In her ethnography of the medicalized dying process in the United States, Susan Kaufman (2005) paraphrases a medical resident’s words about patient objectification: she

*“characterized the first year of her residency training in internal medicine as a period of learning to be disciplined by the bureaucracy to be a cog in the system. Patients were merely an epiphenomenon, she remarked, the objects acted on to ensure the smooth running of the institution”* (14).

Key here is the idea of the patient as an “epiphenomenon”, a word that in biomedicine refers to a physical effect unrelated to a defined causal chain of a disease or treatment, usually not the main concern of a practitioner focused on disease. Susan, Stanley and Roger struggled with not receiving personal attention from practitioners, feeling like one patient out of many under biomedicine. Their encounters represented repetitions for biomedicine, but unique, scary experiences for themselves. Stanley explained his feeling of being routine or one of many in the eyes of doctors:

*“At the hospital where I was, where I had it done [lobectomy]... It’s an operating hospital so obviously you’re not the only one with cancer, you feel as if you’re the only one with cancer but to the nurses and the doctors you’re not the only one, they see hundreds of people all*

*day long and obviously you feel as if you are the only person that's got cancer. I think that's probably what upsets you more than anything. You don't get a lot of sympathy at all."*

Stanley would have liked doctors to see him and his illness as he saw himself in his life outside the biomedical institution, where cancer was unusual, a big deal, and treated with emotional urgency. He transitioned to a biomedical world where he felt cancer was treated as common, even mundane, and his fears and uncertainties treated as irrelevant. He sensed that his routineness translated to lack of "sympathy" from clinicians used to dealing with cancer.

Roger made this point succinctly, stating that his illness is *"scary because it's serious stuff, and it's ... to, to the nursing community it's everyday, but to the patient it's not."*

Susan expressed similar feelings, reacting to the idea of statistics and expressing great uncertainty, ambiguity and confusion:

*"I understand that all this stuff is statistical you know and all I am is a statistic and I might be... From my point of view, I might be a good statistic or I might be a bad statistic, but what you really realise is that they don't know and I ought to have more sense in this because I know about statistics I'm not you know, and but when I became a good statistic you know I'm one of the statistics that's going to recover it's very hard to say how hang on a minute you are only a statistic this could be wrong even though you know that and it just, what it convinces me it's not their fault and they don't know and so that's, I think the only thing that you can therefore do is at all times to the best of your ability try and imagine yourself at the positive end of the statistical thing (laughs) because you just might be, however awful you're feeling you might be that one and it's, yes well, it's a bit like the lottery isn't it, it isn't like people think it is. And even when intellectually I know all this and I'm a mathematician I do understand it, it's sort of, they don't know."*

Susan struggled with the confusion of being subjected to the calculating rationality of biomedical science. Not only did she and her doctors use statistics, but in her mind she "became" a statistic, a good or bad one. Statistics subjected her to comparison with many other (hypothetical) lung cancer patients who had varying outcomes. She "intellectually" accepted herself as one of many cancer patients, and that her fate would lie somewhere among a "distribution" of other outcomes. She wanted to have a "good" outcome of recovery or get lucky in the "lottery". But she felt something else, an existential nagging that she could not fully articulate, an emotional resistance to viewing herself as a statistic. She seemed to imply that the framework of statistics did not capture her experience. She did not see herself as one of many contributing to an overall outcome distribution, but one of one,

personally subject not to overall odds but to her own sense of biographical narrative. The caregivers did not seem to recognize her conflict in this area, and she felt alienated from the biomedical framework.

Susan, Stanley, and Roger felt like epiphenomena in that caregivers treated their diseases while alienating the patient's perceived "selves" from their own care. As Susan put it: *"you're a person who's got a disease not some boring old thing hanging off the side if it."* The progression of their cancers, not their emotional state or thoughts, seemed to singularly concern their doctors. They as people felt considered secondary to their diseases. The word "nuisance" might accurately describe their perceived patient roles.

Roger internalized this "nuisance" dynamic, and it affected his behavior and well-being:

Roger: *"I felt that I didn't want to bother them [the nurses] because that's my attitude, my attitude to life anyway, so I didn't want to make their job any more difficult, but at times I had to ask for things, but I wouldn't ask until it had already got (laughs)... It had already got to me a bit. So, you know, yeah, I would have liked more TLC [tender loving care]."*

The asymmetry concerning the patients as new to the clinic and to cancer, and practitioners as familiar with the illness and the setting, resulted in feelings of alienation and isolation for the patients.

### *Comfort in personal treatment*

Despite overall sentiments of isolation, patients felt comforted when treated as individuals rather than members of a collective pool of cancer patients. Both Stanley and Roger expressed comfort in being taken care of by a particular nurse as opposed to an entire staff:

Stanley: *"We're getting on a lot better talking to the nurses, even my family can phone a particular nurse up whereas before when I had lung cancer, before you couldn't ring and speak to a particular nurse, you had to speak to the sister or the staff nurse that was on duty. But now we can ring up and ask for a particular nurse now at the time and nine times out of ten we're getting through to that particular nurse."*

Roger: *"Yes, er I think you just get... there's a feel good factor about feeling that someone's responsible for you rather than, er, half a dozen nurses any of which could be responsible."*

Having one nurse accountable for them helped Stanley and Roger feel more supported. This helped Stanley talk to nurses, and for Roger it inspired a non-specific “feel-good factor”. Roger and Stanley were glad to have a particular person “responsible” for their health, rather than a larger biomedical system with multiple institutions and caregivers. To have one assigned nurse helped Roger and Stanley by inserting familiar person-to-person interactions in the biomedical process, as opposed to patient-to-system interactions, helping them feel less handled as routine, and more treated as individuals.

Throughout the patients’ experiences, the role of nurses as explainers and companions in biomedical systems was crucial. Nurses could be companion-like guides that helped patients with the confusion of navigating biomedicine. They explained cancer and the biomedical system in terms the patient could understand. Susan explained: “*hospitals are a nightmare so they [nurses]... (laughs) they can be very helpful to have an ally on the inside.*” The phrase “ally on the inside” implies a dual role of nursing of working with and understanding the biomedical system, and translating this understanding for Susan.

Two nurses in particular helped Stanley feel supported, not just medically, but emotionally:

*“And she really did help me get through my operation. She talked to me and explained things to me. Up until then nobody had explained to me in any detail of what was going to happen to me, they just said they [were] going to take part or all of my lung away, they didn’t say anything at all about the operation, how the operation would be carried out. It seems as if they’d [other nurses] got a set time to talk to you and that once that time was up that was it finished. But she [support group nurse] hadn’t got a time limit when you talk to her. It’s the same with the GP.”*

These nurses helped Stanley reduce the alienation he felt as part of a biomedical system that did not prioritize his knowledge (or what he did not know), language or explanatory models. He thought his doctors and other nurses treated him as a complication, secondary to their work on his cancer, concerned with him as a medical object, but not treating his understanding as important. Speaking with nurses who considered his questions and concerns helped him feel less alienated and emotionally cope with his medical experiences. Even though patients experienced aloneness in the clinic, their often fleeting encounters with attentive practitioners helped them feel cared for.

## Support and alienation in personal relationships

In addition to feeling alone in the biomedical realm, Susan, Stanley and Roger frequently touched on the complexities of their personal relationships during their cancer treatment. Patients' loved ones could have important positive roles in their experiences with cancer.

### *The supportive role of personal relationships*

Susan remarked on getting cards from friends and family: *"it's very nice that you're not just a one off sickness."* Her family reminded her that she was not just one of many cancer patients—the way statistics made her feel—but special to other people.

Roger reflected similarly: *"My wife came in every day and some, sometimes twice a day, and I kept sort of wanting to make it easier on her and say, 'No don't come and see me so often', but really I wanted to see her, so..."*

He discussed visits from his family directly after his comments on the routineness of cancer to his caregivers, connecting the two, and implying that his family interrupted his impersonal alienation from biomedicine by making him feel significant on a personal level. He further mentioned his wife and his cancer:

*"She said she'd still love me even if I had no hair! Um, I remember saying to her, 'What if I have no hair on my body either?' and she said, 'Oh that's okay, I'll still love you'. And I said, 'Well, what if I've got no money?' She said, 'Well that's different!' (Laughs) She's a bit of a shopaholic, is my wife! (Laughs). So once I knew it didn't bother other people, then I didn't bother about it."*

In addition to bringing him humor, Roger's wife helped him overcome social stigma of his cancer treatment, and helped him reaffirm that he was "loved", that his disease could not totally alienate him from friends and family. In key moments, personal relationships helped patients feel that they were socially supported, and reminded them of aspects of their life beyond their illness and treatment.

### *Alienation in Personal Relationships*

Despite the support they provided, the patients' loved ones had limited capacity to help them through their illnesses, and patients underwent a degree of emotio-

nal isolation from friends and families who did not fully understand their experiences. Stanley said:

*"I was given a lot of support from the family but they didn't understand how I felt. I felt as if they didn't understand. They was, the family was marvellous with me, all the family, my children and the wife, but I didn't think that they understood how I felt, myself."*

Stanley felt that no matter how caring they were, his family could not understand his cancer, because they did not experience it themselves. In holding this view he implied that his biomedical experience involved distinct interpretive frameworks from those of his family. He felt alienated and alone because of this, at times suffering depression, from which he felt relief only when he talked to other cancer patients in a support group: *"the depression sort of went once I got involved with the group,"* he noted. He continued with advice for other cancer patients: *"Don't get into the depression...Get in touch with other people who've got cancer and talk to them, go and talk to them. Especially if you can get somebody that's in the same frame of mind as yourself who thinks like you."* He identified a frame of mind specific to cancer patients, asserting that contact with others who understood his biomedical treatment experience was paramount in avoiding the depression of alienation.

Susan felt ambivalent about sharing her disease with her loved ones, because she did not want to burden them. She discussed her relationship with her adult daughter:

*"And I think that for her, she knows that she doesn't want to be unhappy, because that will make [me] unhappy and I don't want to make her unhappy and it's, it's quite hard to deal with, because there are things that I want to talk to her about, but I don't want to talk to her about them, because they'll upset her, it really can be quite hard."*

Susan wanted support from her daughter but did not want to transfer her suffering to her daughter. She wanted emotionally protective distance between her daughter and her cancer experience, but protecting her daughter further alienated herself and separated her biomedical experience from her social life.

Some of the people in Roger's life who would normally support him during challenging times found cancer a subject too difficult to handle.

Roger: *"I phoned her [my daughter] up and I said, '[daughter's name] what's .... you haven't phoned me? You know I don't mind, but what's the matter?'* She said, *'Dad, I can't talk about it'. And I suddenly realised that she actually had a big difficulty in just accepting and being able to talk about cancer. 'Dad had cancer'. She didn't want to accept it, and one way*

*of dealing with it was not to talk to me. Not that she didn't want to talk to me, but it's a way of trying to conceal the truth."*

Roger's daughter could "conceal the truth" from herself, and distance herself, because she did not go through the cancer. At the same time, Roger believed that his family's relative distance from the cancer made it more difficult for them to handle:

*"The chemotherapy, which has been very unpleasant, um, but for all of that I think she had a much harder time than me. I think that the family of the person who has actually got it, er, go through much worse, because dealing with it is so much harder. It's easier for me to deal with it – I've got cancer. So I can deal with it, but for my wife it's really hard."*

From Roger's perspective, having cancer made him better equipped than his family to deal with the spectre of the disease. Roger did not feel alone during this time; on the contrary, he felt especially "*cherished within the family, and I've never felt it before, because, well, I've never been ill before!*" His family expressed love and sympathy, but did not share his experience or understand it—helping Roger feel less alone even in his experiential alienation.

## Conclusion

In both medical and personal contexts, Susan, Stanley, and Roger experienced isolation and alienation. In medical contexts, they sensed that some practitioners saw their illness as normal and did not sympathize with their fear. In social contexts outside the biomedical institution, they sensed that even when they received support from friends and family, their loved ones could not fully accompany them through their illness experience due to lack of understanding. However, patients found solace in certain practitioner-patient and social relationships in which they received special attention or support.

Susan, Stanley and Rogers' narratives reflect the need for further consideration of patient perspectives on experiences of alienation: for practitioners to further consider the alienating emotional effects of illnesses as routine within the clinic, and for everyone to reflect on how we deal with illness as a society, to better support people during treatment for illnesses such as lung cancer.

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