Potential Futures: An Ethnography of a Familial Cancer Counselling and Genetic Testing Unit

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Related Thesis Publications

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Abstract

In current Western biomedicine, an accepted and shared belief is that human beings are made up of ‘genes’ and ‘genetic mutations’ which people can inherit from one’s biological parents at the point of conception. Various environmental conditions and factors can also alter genes – thus, genes also mutate over time. With particular genetic mutations identified and considered responsible for illness and disease, inherited mutations are increasingly being used to provide explanations for disease causation and as motivation to reduce or prevent potential associated illness.

In an Australian familial cancer and genetic testing unit, ethnographic fieldwork was conducted over twelve months between 2010 and 2011. In this unit, twelve members of staff worked with approximately nine hundred clients a year referred because of a suspected inherited familial cancer risk. There were four main clues that suggested cancers could be familial, and so warranted referral to the Unit: cancers involving several family members, early age-of-onset of cancer (less than fifty years), multiple cancers in one family or “unusual cancers” (e.g. male breast cancer). Such experiences indicated that cancer was not due to “chance” or “similar environmental upbringing” (like the majority of cancers), but rather due to the genetic inheritance of a “mutation” that was sometimes identifiable by a blood test. The clinical geneticists and genetic counsellors in the Unit were powerful gatekeepers of information. Knowledge and power were exercised in various ways: deciding who became a client, and involving the clients in providing various information including medical histories, genetic material and sometimes the contact details of particular biogenetic relations. Regardless of whether genetic testing was offered to clients, clients received information about their familial cancer risk that

sometimes included information about the precautionary risk-reduction measures they could undertake. These included undertaking regular surveillance screening, the surgical removal of body parts (e.g. prophylactic breast surgery) and family planning measures. In the majority of cases, clinicians offered genetic testing to clients who met their criteria and in whom the clinicians predicted a mutation could be found. Even when results identified a familial cancer mutation, there was no way of telling if, when, and which individuals would develop familial cancer. Familial cancer risk was predictive and not prescriptive, an ambivalent diagnosis that caused and supported the ongoing engagement by the clinicians and the clients around what the diagnosis could potentially mean.

The thesis demonstrates the uncertainties and potentialities surrounding the work of familial cancer risk. It critically examines how the clinicians (in particular) performed and propagated particular ideas and information. There were various complexities present in the work of the Unit including tensions, contradictions and paradoxes, which were a direct result of the uncertainties surrounding familial cancer risk. I demonstrate and analyse the particular ways in which the complexities and uncertainties were experienced and expressed by the clinicians, clients and visitors of the Unit. This thesis adds to medical anthropological knowledge by examining the complexities and uncertainties that surround genetic information and material as both shared and separable; the clinical emphasis of “genetic counselling”; genetic and social families; a client’s health status when considered at risk of familial cancer; the Unit’s formal practice of risk notification; the right to be informed and not informed; and staff competition surrounding mutation identification which reflected engagement with uncertainty and was linked with personal and broader potentialities.

Important Notes

The abbreviation “Unit” is used to refer to the familial cancer counselling and genetic testing unit throughout the thesis for easier readability.

The names of places, organisations, participants and other identifying factors are replaced by pseudonyms in order to protect the anonymity of all participants. The removal and modification of identifying information in order to conceal the identities of all the participants was an ongoing process. Confidentiality issues were discussed with the staff of the Unit both prior to undertaking the research and subsequently discussed as necessary. To further help protect the identity of the participants, a one-year embargo has been placed on this thesis.

At the time of writing (and its subsequent readings), the ethnographic findings, occurrences and descriptions have occurred in the past. Thus, this thesis is written in the past tense rather than an ethnographic present. Writing in the present tense carries more authority than the past tense can evoke, but it implies a view of the community, and the events, ideas and behaviours as frozen in time, predictable, rule-determined and unchanging (Murchison 2010, p. 207; O’Reilly 2005, p. 137; Sanjek 1991, p. 612). By writing in the past tense, I instead emphasize the historical nature of the findings and therefore the potential for change (Murchison 2010, p. 207).