

Family-Centred Healing At Home: A
Samoan Epistemology of Samoan
Families' Experiences of Home Dialysis
and Home Detention in Aotearoa/New
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Family-Centred Healing At Home: A Samoan Epistemology of Samoan Families' Experiences of Home Dialysis and Home Detention in Aotearoa/New Zealand

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Abstract:

Home dialysis and home detention are home-based public services increasingly used in Samoan households living in Aotearoa/New Zealand. They are cheaper than institutionally-provided hospital and correctional services and save the government millions of dollars; savings which do not seem to be transferred to the households which switch to home-based services. This thesis considers the role of housing in Samoan families living in Aotearoa/New Zealand, both symbolically and practically. It analyses in depth the way these two different public services are adapted within the home built environment and the effect these have on the lives of Samoan occupants.

The quality of housing and built environments are a vital and significant component of home-based services, yet, largely ignored in the literature and state policies as having an effect on the health of occupants. In this qualitative research I used a multiple-case study approach to investigate the housing experiences of five Samoan dialysis patients (n=4) and their carers (n=8); and two Samoan home detainees (n=2) and a sponsor (n=1). Using an iterative approach of the Photovoice method, disposable cameras were used by the participants to produce photographs about their experiences.

In consultation with Samoan elders, I also developed an epistemological model of Samoan health and well-being based on the traditional house and descriptions of tides and winds. The participants' photographs and in-depth interviews in the Samoan and English

languages were matched to the three stratified areas of the Samoan traditional dwelling: front of house, middle of house and back of house. Key informant interviews with public service officials were also analysed to provide important information about the Wellington Hospital Renal Unit (n=2) and the New Zealand Prison Services of the Corrections Department (n=5).

Home-based services, when compared to hospital and prison institutional services, gave the participants many advantages. These included the convenience of being at home, reduced transport and travelling costs, spending more time with family and friends and in some cases participation in vocational and rehabilitation programmes. Samoan culture provided a useful framework for families to respond to the sensitive issues and obligations associated with palliative renal care, death, spirituality, gender arrangements, transplantation, cultural identity and restorative justice.

Other unexpected and less favourable outcomes associated with home-dialysis were fuel poverty, lack of indoor storage, minimal spatial heating and issues of waste disposal. Samoan participants expected far more support at home from public authorities than they in fact received and many of them experienced stigmatisation and social isolation. These everyday experiences forced some dialysis patients to give up home-based services and return to hospital services, which are more expensive. For some home detainees, spousal violence and problems with other family members increased because they were confined at home. They also failed to gain access to vocational and rehabilitation programmes.

Finally, while there was general agreement by participants that home-based services are a positive and effective way of increasing individuals' independence and freedom, greater improvement of home built environments as well as increased assistance from public authorities is needed so that families can better meet the formal requirements of home dialysis and home detention. The results, recommendations and the photographs produced by the participants were reported directly to the key governmental stakeholders supporting the study.

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detention; Samoan tattoo; front of house; back of house; middle of house; urban youth gangs; private household space for public services; electronic monitoring; electronic bracelet; Pacific prison officers; compliance at home; isolation at home; families and the State; caregivers; home detainees; home imprisonment; decentralisation; challenges of home dialysis; fear of haemodialysis; boredom on home detention; breach of home detention; forgiveness and punishment; HNZC renovations; patient independence; cold houses; elderly caregivers; kidney transplantation; Samoan deaths; Segregated status; Samoan communities; Samoan populations in New Zealand; Samoan protocols; Samoan culture; links between primary and secondary care services; support services at home; children of prisoners; unresolved grief; privacy at home; surveillance equipment; carer roles; patient transport problems; medical waste; storage problems for dialysis; Va Tapuia; House of Healing; House of Ashes; primary health care and dialysis patients; prisoner accommodation; costs of dialysis; costs of home detention; the primacy of home; Samoan epistemological approach; housing availability for big families; housing and the poverty trap for Pacific families; approved premises; housing for home detention; the advantages of home detention; the advantages of home dialysis; Samoan traditional houses; Samoan religion; Samoan graves; care protection advocacy; recruiting Pacific participants; qualitative research; visual methods; photo documentary with Pacific communities; visual data; indepth interviews; coding and data analysis; analysing photographs; housing tenure for dialysis patients; housing tenure for home detainees; institutional setting and home setting; waste disposal and home dialysis; ghosts and mirrors; photo images; electricity bills and home treatments; non-clinical issues and home-based services; electrical appliance for medical treatment; older prisoners; private rentals

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