

ABSTRACT

This mailed survey of nurses in all (111) NSW aged care facilities with HD affected residents, used a custom designed questionnaire in a triangulated, exploratory design. It was undertaken by an HD specialist nurse into the previously un-researched field of the nursing challenges in that setting. Knowledge was sought, through descriptive and correlational analysis of fixed choice and open-ended questions, of the facts of the affected resident profile (N=63). Similarly, nursing opinions were obtained on the following: unsatisfactory aspects of care provision, the impact of internal resources and the HD nursing role and its support.

High return rates (57%) from experienced (77%>15 yrs), mainly registered nurses (85%), indicated contributing factors to their dissatisfaction included their lesser HD experience and insufficient knowledge of this rare condition, in spite of specialist education (58%) and multidisciplinary support. The accommodation was considered especially inappropriate for the younger HD affected residents (M=58yrs) and by the less qualified nurses (AIN's) in hostels as well as the more experienced nurses. However, it was the age differential of HD affected residents (64%<65yrs) with their very elderly companions (6%<65yrs), and the unattractive and time consuming characteristics of the disease (especially ill-understood "antisocial" behaviours) that were seen to predispose them to attract *deviance* status. Although in the minority, and a "Cuckoo in the Nest," overt evidence of stigmatisation was not evident. Reformulated *Deviance theory* for nursing, (Trexler, 1996) suggests the possibility of redefinition as "accidental deviant" by education should increase tolerance of carers, other residents and their families. Approximately 32 additional long stay HD beds are needed plus more equipment and education for the aged care facilities. The outreach model of support was strongly endorsed.