The sustainability of self-care in two counties of Guizhou Province, Peoples’ Republic of China

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Summary This paper presents the findings of a follow-up survey conducted in two rural counties of Guizhou Province, PRC where a programme to prevent disabilities amongst leprosy affected people had been conducted. An initial 3-year programme had been conducted. One year after the final evaluation of the programme, a team was deployed to conduct a survey in the area. The objective of the survey was to establish the level of adherence to self-care.

It was found that 87% of the sample of people living in leprosy villages that were surveyed (n = 31) and 50% of the sample of people living in general communities (n = 50) had continued to apply self-care. Interviews with family members suggested that 18 of the 27 self-care practising subjects living in the leprosy villages received encouragement or active support from family members (9 were single people). Twenty three of the 25 self-care practising subjects living in the communities also received family support (2 were single people). Family support was a highly significant factor influencing adherence in the community (OR = 15·8, CI = 3·0 to 83) but it may not have been the primary motivating factor in the leprosy villages where single people were just as likely to have adhered to self-care than people who were living in families (OR 0·5, CI = 0·06 to 4·2).

The prevalence of foot ulceration among that population was recorded but a hypothetical association between the prevalence of foot ulceration and self-care adherence could not be investigated due to insufficient data to address the potential effects of confounding variables. Thirty-eight percent of subjects who did not practice self-care presented with ulceration or foot cracks (n = 29) compared with only 25% of people who did (n = 52).
Introduction

Self-care for the prevention or management of secondary disabilities is an intervention of increasing importance. The Innovative Care for Chronic Conditions (ICCC) is a model of health delivery that was designed specifically to address the concern over the burgeoning global issue of chronic conditions which impact on peoples’ function. The essential features of the model are that productive interactions between appropriately informed and trained people, community partners and adequately prepared multidisciplinary teams of health workers are developed. It is considered that the model will function optimally when all members are appropriately informed, motivated, and prepared with ‘skills’ necessary to manage chronic conditions. Where the model departs significantly from earlier models of health delivery is that control over the management of chronic conditions is transferred to the affected individual. The ‘skills’ required are those that empower people to undertake self-care. These issues were discussed in more detail by Cross.

The efficacy of self-care as an intervention for impairment control is becoming more apparent. A significant early publication on the topic was that of Benbow et al. which demonstrated that self-care was very much more than just ulcer management. Since the Ethiopian study, Cross and Choudhary also demonstrated that the impact of self-care could extend beyond the lives of people who practice it. A challenging issue, however, is whether self-care is a sustainable intervention. Commitment to self-care for impairment management requires far more than a temporary departure from normal activities so that a condition can be ‘treated’; it is a behaviour to be inculcated as a life skill. This study is an examination of the adherence to self-care 1 year after any formal supervision had ceased.

Guizhou Province in the Peoples’ Republic of China (PRC) continues to yield a small but persistent number of new cases of leprosy. The average number of new cases since 2000 was 200 per annum which accounts for approximately 25% of all cases registered in the PRC since 2000. Of the new cases that were registered in Guizhou, it was recorded that 20–25% presented with WHO grade 2 disability at diagnosis. According to surveillance data from the Guizhou CDC, in 2007, there were 18,892 people living in Guizhou who had been treated for leprosy. Of this number 60% (11,330 cases) had disabilities due to leprosy.

Following a pilot POD project initiated and implemented by the National Centre for Leprosy Control (NCLC), Nanjing, a prevention of disability and rehabilitation programme was designed and implemented by the Guizhou Institute of Dermatology in partnership, first with The Leprosy Mission International and then with American Leprosy Missions (ALM). The plan was to implement a programme based on the same objectives of the NCLC POD Pilot programme. There was a strategy to introduce POD, in a phased manner, throughout the province (the final phase of the programme is planned for implementation in 2008). Each phase extended over a 3-year period. During the 3-year phase in Qianxinan prefecture, a general range of measures for impairment prevention and management were instituted, but the essential objective of the programme was to create and establish a sustainable culture of self-care.

Field responsibility for teaching self-care, motivating people to apply it, monitoring its effects and recording the results was the responsibility of local government doctors who had undergone training from senior personnel in the Guizhou Institute of Dermatology and also from the NCLC. The programme was closely monitored with ultimate responsibility being assumed by the director of the Guizhou Institute of Dermatology.
From June 2000 to June 2003, in partnership with ALM, the second phase of the programme was instituted in Qinxinan Prefecture and Anshun City. From these locations four counties had been selected for implementation of the programme. In February 2004 the programme was evaluated. On the basis of findings recorded, using impairment summary forms (verified independently through observation, examination and interviews), it was recorded that the outcomes of the intervention had been very satisfactory, but concern was raised over the sustainability of self-care after the withdrawal of all forms of support. The full evaluation report is available on application to the Guizhou Institute of Dermatology or ALM. A paper detailing salient features has been submitted for publication (Leprosy Review).

From April to August 2005: i.e. 1 year after which all support had ceased, a survey was conducted. The objectives of the survey were to establish the extent to which people in two of the counties, Xin Yi and Pu An, had continued to practice self-care and whether there was evidence that continued self-care was associated with sustained impairment control. Four counties had been included in the original programme but Xin Yi and Pu An were selected for follow-up, because both counties had community and leprosy village populations. Ping Ba County did not have a leprosy village and although An Shun City did have a leprosy village, the population was atypical in that all of the inhabitants lived alone (no family members).

Materials and Methods

Public health personnel in the two target counties were trained in data collection and were familiarised with technical requirements. They were tasked with tracing subjects and conducting interviews and physical examinations.

Of 218 people with one or two insensitive feet who had participated in the POD programme implemented in 2000, a sample of 81 people were randomly selected. Thirty one people were living in two leprosy villages (population = 67) and 50 people were living in general rural communities (population = 151). All subjects had participated throughout the 3-year POD programme.

Results

People living in leprosy villages differed from community dwellers only on the number of subjects living with families and the number of people in the families of the respective groups (Table 1). The entire population was rural.

It was apparent from the data that people who lived in leprosy villages had adhered to self-care to a greater extent than people who lived in the community (Table 2). Village dwellers who lived in families were only marginally more likely to have adhered to self-care than single people, suggesting that it was the leprosy village environment per se that was beneficial for self-care (see discussion).

In the general communities 23 (48%) people who lived within a family were found to have adhered to self-care practices, but since only two community subjects lived alone, it was not possible to ascertain whether living in a family was more advantageous than living alone (Table 3).

Using an interview protocol it was recorded that, where subjects lived within families in the leprosy villages, all the families understood the need for self-care, accepted the validity
of the intervention and actively encouraged their leprosy-affected member to conduct necessary self-care procedures. The strength of family support given to people in leprosy villages may have had a significant effect on self-care behaviour in that environment, but it was also noted that single people in the leprosy village had mostly adhered to self-care too.

The situation for subjects living in families in general communities was different. It was very clear that active family support was a significant factor that influenced support.

Footwear

Adherence to advice to wear appropriate footwear was also considered because the use of protective footwear is an aspect of self-care behaviour. During the POD programme (June 2000 to June 2003) all people with sole insensibility were supplied with soft soled canvas shoes. When the follow-up survey was conducted in April 2005 it was found that 23 subjects from the leprosy villages (74·2%) and 42 subjects from general communities (84·0%) continued to wear appropriate footwear.

Disability Management

Following examination of all review subjects it was recorded that 11 (38%) out of 29 subjects who did not practice self-care presented with ulceration or foot cracks (Table 4). The percentage of subjects with ulcers/cracks amongst the group that did practice self-care was less (13 subjects; 25%). Although the OR suggests that the group that did not practice

| Adherence | Yes | No |
|-----------|-----|----|
| All village dwellers | 27 | 4 |
| All community dwellers | 25 | 25 |
| Village dwellers living with family | 18 | 2 |
| Village dwellers living alone | 9 | 2 |
| Community dwellers living with family | 23 | 25 |
| Community dwellers living alone | 2 | 0 |

Table 2. Adherence dependence on place of domicile and family living
self-care was not at a greater risk of sole skin damage the result should be considered with caution due to multiple possible confounders (see discussion) and the small sample size.

Discussion

The results of the survey demonstrated that subjects who lived in the leprosy village were more likely to have adhered to self-care practice than people who lived in general communities (87% of village people compared with 50% community people). The extent to which family support affected adherence in the leprosy villages remains unclear. In the leprosy villages people were just as likely to have been conducting self-care whether they lived in families or not.

Of the 50 community subjects, all but two lived in families (the two solitary dwelling people were found to have adhered to self-care). The results of the survey demonstrated that reported family support in the communities was highly significant. However it was reported that there were 10 people (20% of the sample) who did receive family support, but still failed to adhere to self-care practices. The authors postulate that unfavourable environmental factors (social and physical) in the community might have confounded the attempts of some family members to persuade their leprosy-affected member to conduct self-care.

There were incentives and generally more support mechanisms for people who lived in the leprosy village. In one of the villages there was a zealous village ‘nurse’ who gave assistance to some of the elderly and more frail people who lived there. Every leprosy-affected individual received social welfare support in cash and in kind from the local government. Whilst they were still compelled to work, they were not as pressurised to support their families as people who did not live in the village would have been.

Whilst isolation had meant that village people were relatively dislocated from the normal social order of Qianxinan, this study suggests that the social structures that the villagers had

| Table 3. Adherence dependence on family support |
|-----------------------------------------------|
| Adherence | Yes | No | Odds ratio with 95% confidence interval |
| Village dwellers – family gave support | 18 | 2 | Odds ratio is not calculated when 0 values are included |
| Village dwellers – no family support | 0 | 0 |  |
| Community dwellers – family gave support | 21 | 10 | OR = 15·8; CI 3·0 to 83 |
| Community dwellers – no family support | 2 | 15 |  |

| Table 4. Skin integrity |
|------------------------|
| Ulceration or cracks | No | Yes | Odds ratio with 95% confidence interval |
| Adhered to self-care | 39 (75%) | 13 (25%) | OR = 1·8; CI = 0·69 to 4·9 |
| Did not adhere to self-care | 18 (62%) | 11 (38%) |  |
developed may have provided them with an adequate alternative. It appears that amongst other developments, a culture of self-care may have developed in the village. If self-care had become a cultural norm, people who deviated from that norm may have been subject to censure from others.

Another reason why people in the village demonstrated greater commitment to self-care may be related to social acceptance. Paradoxically, in the relative restrictions of their environment, villagers perhaps enjoy greater freedom from the effects of acute enacted stigma than people who were never confined. Without the psychologically disabling effects of insults, people may have been less prone to depression and anxiety disorder which can ultimately affect adherence to positive health behaviour.11

During the project period, people living in the village will have had more interaction with health care workers and therefore more encouragement and admonition than people in the community. This was also likely to have affected the outcome.12

Locke and Latham (cited by Schwarzer and Fuchs12) reported that when environmental barriers, whether perceived or actual, are too great, people may not pursue positive health behaviour, regardless of strong motivating factors. Environmental barriers can include physical, social and/or psychological factors that an individual feels powerless to overcome. Environmental barriers in the general communities of Qianxinan may have been, or may have been perceived to have been, too overwhelming for some. The people were rural poor who worked mainly as agricultural labourers. The physical hardship of labour for low wages combined with the stress of discrimination is likely to have compounded difficulties imposed by leprosy-related impairments and the activity limitations associated with them. As environmental barriers to positive health behaviour, those factors were probably significant. Considering the subjects lived in such an extremely challenging environment, it is encouraging to consider that 50% of the target population had adhered to self-care.

A reason that half the population in the community did appear to have persevered with self-care is suggested here; it is speculative, but based on well researched theories of health behaviour. Schwarzer and Fuchs12 cited Locke and Latham who recorded that, above all other factors, it is the relative levels of perceived self-efficacy that determine individuals’ motivation to act.1 They ascertained that not only were people with high self-efficacy likely to apply health advice, but that they were also more likely to persevere with recommended actions. They explained that, in the first instance, an individual’s commitment to behavioural change is related to the anticipation of either optimistic or pessimistic outcomes. Such outcomes are relative to an individual’s level of self-efficacy. They also explained that, having made a commitment to adopt a particular behavioural change, people with high levels of self-efficacy invest more effort and persist longer than those with low self-efficacy. High levels of perceived self-efficacy are also associated with people who explore their environments and who actively seek to create new situations and solutions to solve problems. Furthermore, such people are also associated with an ability to recover quickly from set-backs and are less easily diverted from their goals.

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†Perceived self-efficacy is defined as people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes.’(Bandura 71).13
Skin Integrity

Eighteen (62%) out of 29 subjects who did not adhere to self-care did not present with a recurrence of cracks or ulcers, whilst the same observation was recorded for 39 (75%) out of 52 people who did adhere to self-care. The OR of 1·8 (CI = 0·69 to 4·9) should be interpreted with caution because it failed to reach statistical significance, and because of the complexity of factors affecting skin integrity. The study did not consider other variables that will have influenced the outcome: the extent of disability, distances walked on a daily basis, types of activity, age, nutritional status are some important variables.

The authors postulate that further intervention, with the objective of raising the socio-economic status of the target population, might effect better impairment control. It could reduce the perceived and actual burdens associated with the responsibility for contributing to family income, but it could also provide more appropriate occupations for people with compromised nerve function. It is also our opinion that offers of opportunities to avail of economy enhancing programmes could act as a motivating factor for applying self-care activities.

Conclusion

Self-care had become a routine for 87% of people living in leprosy villages in Qianxinan and for 50% of people who lived in general, rural communities of the prefecture. The more intense social mechanisms in the village appear to have favoured adherence, but the role of family support *per se* is unclear because such a high proportion of people in the villages did practice self-care routinely (the number of people who did not practice self-care were too few to allow further analysis). Family support for people affected by leprosy who lived in the communities was a very significant factor affecting adherence to self-care.

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