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The meaning of care for older Chinese caregivers: an exploratory model of positive caring

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THE MEANING OF CARE FOR OLDER CHINESE CAREGIVERS: AN EXPLORATORY MODEL OF POSITIVE CARING

by

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Lingnan University
Hong Kong
# The Meaning of Care for Older Chinese Caregivers: An Exploratory Model of Positive Caring

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ABSTRACT

Caring is often a highly personalized and individual activity. Through in-depth and searching interviews with two older care-givers, this study explored the determinants that help to sustain carers in their long-term care role and proposes an explanatory model for sustaining care. Attempts were made to uncover those meanings held by Chinese care-givers in interpreting their roles in a positive way despite the enormous demands placed on them by care-giving or, if they interpreted their care giving negatively, the attitudes that sustained their giving of care. Narrative accounts were obtained through separate interviews (conducted by two experienced social workers) asking open-ended questions guided by prescribed themes (determinants). Content coverage included basic demographic variables: sex, income, education level, religion, age; family responsibility/reciprocity, doing what needs to be done, caring personality, satisfaction and gratification, friendship and company, improved relationship, personal growth and identifying specific rewards of care-giving for self (i.e. the care-giver). The respondents were asked to describe all the above in relation to providing the care as they themselves perceive these domains, then were encouraged to provide a detail explanation for how these domains were encouraging/discouraging them to continue to care. Similar description and explanation given by the two care-givers were extracted as congruent to the prescribed themes - hence these consistent findings serve to inform the formation of a crude explanatory model for care givers’ commitment to long term care. The study also informs practice in identifying and sustaining good care-givers.

Keywords: Meaning of Care-giving, Chinese elderly care-givers
1. Introduction

Studies in Hong Kong and internationally have shown that care-giving, especially in long-term care, can be a stressful experience for the care-givers (Chiriboga, Weller & Nielsen, 1990; Stoller & Pugliesi, 1989; Poulshock & Deimling, 1984; Clipp & George, 1990; George, 1987). However, research on the acts and process of care-giving has consistently focused on its association with stress or burden, and has generally been perceived rather negatively. However, the extent and nature of care-giving, good or bad, and the attitudes of individual carers, have not been a systematic research concern until recently.

There are few published studies looking at the positive ‘reinforcers’ of care-giving. The nature and reasons for family care-givers in particular continuing to shoulder the bulk of very difficult tasks are relatively less explained than the negative aspect. If the majority of the care-givers still keep on loyally with their role, in spite of the stresses or burden induced by care-giving, there must be some factors that facilitate this or determinants that allow them to persevere. The present paper aims to uncover whether these factors exist and if so to attempt to identify them. A small focused sample of two Chinese care-givers in Hong Kong were interviewed in depth, and the study tries to postulate a model for positive experience of care-giving.

1.1. The Meaning of Care-giving

While providing care to one who needs it can be interpreted both as a taxing or a rewarding personal experience, perhaps as both at varying times, researchers studying care-giving have mostly documented the stresses of care-giving and the negative
consequences of being a caregiver. Care-giving activities, according to most studies, might result in negative impacts for the care-givers. For instance, Chiriboga, Weller & Nielsen (1990) found that care-giving, especially when care-givers were forced to give care, could result in impairment of well-being; Stoller and Pugliesi’s study (1989) established that care-giving in all situations gave stress and Poulshock and Deimling (1984) found that care-givers took care-giving as burden. Clipp and George (1990) indicated that long-term care-giving usually led to financial hardship to both care-givers and the cared and George (1987) established that continuous care-giving gave rise to many health problems. The positive outcomes of care-giving have received considerably less attention and are in need of more investigation and documentation.

From a service point of view, it would be invaluable if a rewarding, or a less negative, care-giving experience could be recognized and sustained. However, in the absence of substantial literature and empirical studies, the first step is to establish what care-giving actually means to those who are happy to persevere their care.

So what is the meaning of care-giving? Until now, there has not been a standardized definition for this. A popular concept adopted by most is Giuliano, Mitchell, Clark, Harlow and Rosenbloom’s (1990, p2) definition as "positive beliefs one holds about one's self and one's care-giving experiences such that some benefits or gainful outcomes are construed from it". Such a definition renders many interpretations possible.

Positive beliefs in care-giving have been further elaborated by various researchers. They may be a range of aspects, for example, self-image uplifts as a result of public
recognition (Kinney & Stephens, 1989); there may be traditional care-giving ideologies, such as family virtues, religion (Lawton et al., 1989); care-giving rewards (Schwartz & Gidron, 2002); positive feelings toward care-giving (Cohen et al., 2002); personal gain and management of meaning, such as praises from others (Pearlin, Mullan, Semple, & Skaff, 1990); and there may be an active search for a meaning through care-giving (Farran et al., 1997). Despite the variations in use and application of these terms, making sense of or giving meaning to care has been identified as the key variable in these studies.

Farran (1997) examined care-giving from an existential perspective and asserted that difficult care-giving experiences provide care-givers with opportunities to search for ultimate meaning in life. Others in explaining the perseverance have been adopting a more socialization perspective where care-givers’ values and philosophy were formed within their social milieu – which in turn shapes their responses to care-giving (Frankl, 1963, 1978; Pearlin et al., 1990). However, such explanations still cannot account for variations in the dilemma ‘one would care when the others in the same family do not’, or in ‘one is willing to care for life and the others just do it for a few weeks’.

Noonan & Tennstedt (1996) have taken the idea further in their study investigating care-giving meanings. They asserted that there are two components of personal experiences which help to sustain the care. One is a cognitive adjustment process which attributes a no-regret belief to care, and the other is an emotional gratification - which is the satisfaction one finds when performing the care-giving role. The study involved qualitative interviews with 48 informal care-givers of older people in the United States. Based on answers when questioned why they would care, various themes were developed: family responsibility/reciprocity, doing what needs to be done, caring personality,
satisfaction and gratification, friendship and company, improved relationship, personal
growth and identifying specific rewards of care-giving for self (i.e. the care-giver). These
themes echo the presence of both a cognitive dimension and an emotional aspect to care.
Furthermore, there are two dynamic processes involved in generating the care-giver
meaning: the search for meaning (attempting to make sense of care-giving situation) and
the establishment of meaning (experiencing care-giving as meaningful relationship). The
findings of Noonan & Tennstedte (1996) make it clear that care-giver’s own meanings of
care are strongly connected with why they persevere in their roles. In this regard, Pearlin
and colleagues (1990) suggested meaning could be ‘managed’ for the justification of
action. The process consists of a reduction in expectations and a use of positive
comparisons – using a reference point worse than your own situation. In addition to this,
Reker (1991) proposed that such managed meaning is also transformative in nature. That
is to say, people rationalize other events for the same meaning by transforming how they
think and feel about a specific situation, hence creating something new for themselves
each time they do so in the process.

In applying these concepts in a real life career of a care-giver, he/she supposed to
equip with a caring personality (i.e. pre-caring conditions), then is required to have an
ability to cope cognitively by generating meanings for care-giving (i.e. making sense of
what s/he does, producing their own meanings) and by acquiring a positive self-
evaluation towards what s/he does (i.e. a self-reinforcing cycle to continue and sustain
care, justifying their experience and action). Roles of external factors (e.g. social support,
the praise of others) are therefore less crucial and are expected to act on as reinforcers in
a self-reinforcing cycle.
1.2. Objectives of the Study

To explore whether the above is indeed the case for the care-givers of elderly Chinese, the present study attempts to devise an exploratory model of sustainable care-giving, by looking at:

1) pre-caring conditions such as the caring personality;
2) the production of meanings by the care-givers under those themes such as family responsibility/reciprocity (e.g. spouse responsibility), friendship and company, and doing what needs to be done;
3) the justification of experience and action in areas such as improved relationship, personal growth and other forms of self-rewards; and
4) information found in the study, a crude explanation of sustainable care giving

2. Method

Research studies of how people make justification or decisions on providing care are arguably better suited to qualitative than quantitative methodologies. These include situation simulations, introspection and thinking aloud (Tanner, 1982; Eddy, 1984; Arkes and Hammond, 1986). The present study hence employed in-depth interviews in exploring the process within which the selected subjects (N=2) gave explanations of why they would persist to care. The interviewers (N=2) first asked the subjects to freely give an account of their caring history in which the interviewers picked out situations that fell within relevant dimensions (guided by the interview guidelines containing open-ended questions covering eight themes for sustaining care-giving (Noonan, Tennstedt & Sharon, 1996) in the order as laid out in the objectives. Additional themes not covered by the existing ones would be created as a new theme category. Retrospection was used to trace
the steps involved in one’s thinking on providing and sustaining care. Thinking aloud was to encourage the respondents to invoke and to articulate what their judgements (justifications) were for continuing the care. Following this track, the interviews were tape-recorded, transcribed and finally fitted into a verbal protocol analysis frame.

Sampling was by targeting at known care-givers who were willing to be interviewed. The inclusion criteria were respondents aged 60 or over, considered by the researchers as having a difficult care-giving experience, having long-term care-giving experience (minimum of two years) and still providing care, and having a positive attitude to carry on care. As the study aimed to search for common determinants for continual care, another subject with similar inclusion criteria but with as many different traits as possible was selected for cross-checking (i.e. for converging to the common themes of determinants) the findings common in both subjects. Using two subjects in such a case obviously does not provide exhaustive findings covering all possible meanings, but the results would be both illustrative and additive to similar studies in the future. The model or explanation would therefore, as stated, be essentially exploratory.

3. **Data Collection**

Data collection was made through an in-depth interview with an interview guide covering basic demographic variables including sex, income, education level, religion, age; physical variables including self-assessed health status, chronic physical symptoms and own ability to care; psychological variables including self-assessed mental health, stress, depression and, social variables including family support, family cohesion, relationship with the cared person, leisure time, competing responsibilities, informal and
formal support (see table 1). The respondents were asked to describe all the above as they themselves perceived these domains, then were encouraged to provide a detailed explanation of how these domains were encouraging and/or discouraging them to continue to care. Two very experienced social workers were employed for the interviews as they were proficient in delineating facts, feelings and judgements and in dealing with respondents’ emotions so triggered by the interview.

Data obtained in the interviews were transcribed separately by the two interviewers and were organized to fit into the proposed framework of determinants (i.e. following the themes); interviewers were also asked to generate new categories for findings not fitting into the prescribed categories. Then the two coded data sets were compared for common determinants and explanation. An analytical summary was finally produced to explain why and how one might be so committed to the demanding caring role.

4. Findings

Demographic variables such as age, sex, class, income, health status etc. did not seem to pose any effects as important pre-conditions or on their justification to care. It would appear though these might have affected the choices for means to care. For example, Mrs. B, as a middle class female who felt that her physique was not up to shouldering 100% of the care, would choose to supervise a maid to care for her husband.

4.1. Pre-Caring Conditions

Probably not every one is suited to being a care-giver as a care-giver should have certain pre-requisites. Likewise, there were some pre-caring conditions commonly found
among the two care-givers. Their tough personality or “never give up” attitude; their cognitive coping strategies employed, including reduced expectations to match with reality, seek actively for solution, and positive self-evaluation; commitment to marriage; as well as their care-giving philosophy.

4.1.1. Tough but Caring Personality

The original theme was on caring rather than a tough personality, but in our findings, care-givers revealed that they had to be tough as well as caring in order to sustain their role.

4.1.2. Life Philosophy

Having a life philosophy which makes the care-givers feel obligated was also evident among the two respondents. They upheld a rather high level of commitment and obligation towards their spouse, because of what they thought they should do. As they said, ‘you would do that even to your friend, and this is your family’.

4.1.3. Spiritual/religious Support

One of the two cases (Mr. A) was a Christian. He firmly believed that God was overcoming the problems with him, helped him to transform from mere suffering to care with meaning and purpose. According to Mr. A, the Christian faith bound them (husband and wife) together for a mutually shared experience leading to another life in God’s kingdom (life beyond death). It was evident that, for Mr. A, a religious faith was conducive for him to commit to the caring role.
4.2. Production of Meaning

The two care-givers did in the course of the interview emphasized that caring for their loved ones was no easy task. Time and again, they were finding the caring experience very difficult, so they would not consider the whole process as a joyful one. The most important aspect of their care was that, as they felt, each trivial task in the caring process was meaningful to themselves - a feeling which made evident that they themselves were the best one to provide care. The following themes were salient and explained, to a larger extent, the commitment of life long care for a loved one. These themes also helped to explain, apart from sustaining positive attitude to care, the mediation of negative feelings in the process of care. Slightly different from the original themes, an additional theme of ‘love’ was strongly emphasized. As these themes and explanations formed a rather important part of the theorizing, some verbatim extracts are given:

4.2.1. Love

This theme noted a strong sense of taking love as a life long commitment on the part of the care-givers, while friendship and companionship were for both to enjoy. It was also observed that ‘doing what needs to be done’ was subsequent to obligation arising out of love – it was love that bound tightly the relationship, hence they were required to do what needs to be done for their loved ones.

*Summarized statements by researcher:*

- a matter of love and commitment
- emotionally and/or spiritually tied to each other
Direct quotations:

- “It is a matter of love. I never think of giving up because the passion and love between us is true.” (Mr. A)
- “We have known each other since courtship in secondary school. We had been together for over 50 years.” (Mrs. B)

4.2.2. Commitment and Responsibility

What the care-givers said were more than family responsibility or reciprocity. Their determination to care for life was referred to as a vow, a public declaration and an unquestionable responsibility.

Summarized statements:

- Taking a spouse meant a promise to care for life
- It implies a must to take care of your partner in all situations
- Marriage is for life

Direct quotations:

- “It’s natural that you have to care for your spouse, unless you are ‘cold-blooded’ mammals! It’s our commitment.” (Mr. A)
- “I’m his wife, it’s natural for me to take care of him.” (Mrs. B)

4.2.3. Friendship and Companionship

Similar to previous studies, our findings also showed that friendship and companionship was one of the reasons for commitment to care.
Summarized statements:

- knowing and being together for more than 50 years
- enjoying the feeling of togetherness
- being the companion of the another half

Direct quotations:

- “I would cook all her favourite food. She ‘supervises’ me in how to cook and I simply follow.”
- “We are going to accompany one another until our last day.” (Mr. A)
- “We have been together for so many years, we spend the days together. I don’t know what to do if I were no longer take care of him.” (Mrs. B)

4.2.4. Gratification and Satisfaction

The gratification stemmed from the cared to the care-givers’ praising themselves for what they have done, while satisfaction was gained from being appreciated by others:

Summarized statements:

- It was always gratifying for the care-givers to see improvements in the person for whom they cared; the results of caring were directly seen as care-givers’ efforts
- Neighbours and friends’ praise were important in sustaining a worthwhile commitment to a demanding job with little material rewards
- Gratification and satisfaction were gained through interpreting the caring experience positively
Direct quotations:

- “When I see her improvements, it’s a kind of happiness to me! I am glad that she’s much better than before because of me.”
- “They treat me as a ‘role model’ (in the mutual support group)!” (Mr. A)
- “It is my concern to keep him in good condition, to make him happy, to take him to join the caregivers programs.”
- “Others were surprised of my knowledge in medicines.” (Mrs. B)

4.2.5. Personal Growth and Development

It was noted that caring was also a path for personal growth and learning. In order to provide better care, care-givers equipped themselves with improved caring skills. Having provided better care and seeing the results, care-givers have adapted and modified previous less-rewarding skills and attitudes, further justifying their productive existence:

Summarized statements:

- The caring experience was a learning experience
- So many things to learn in providing better care
- Only being the care-givers then certain feelings and emotions could be understood
- Enriching life

Direct quotations:

- “I have learned how to lift her, take care of her through attending seminars.”
- “Without going through this pain and suffering, I could not have learnt how to treat my friends in times of difficulties... I learned a lot from this caring experience.” (Mr. A)
“Maybe it is an opportunity for me to perform my unaccomplished role of child minding.” (Mrs. B’s children had all been taken care of by housemaids)

4.3. Justification of Caring Experience and Action

It was clear that both respondents had gone through a cognitive appraisal of their caring experience and actions, and had finally come to justify these to repeat the self-affirmative cycle. What could be described here was a cognitive process of making sense of what they did, perhaps rationalizing it, and then justifying it as a positive (rewarding) experience and action. The two processes resembled a cognitive coping strategy within which life events were managed or manipulated to have appealing meanings. As a strategy of coping, both cases recognized and appreciated the present condition by reducing expectation on the outcomes of their spouses’ conditions; by actively searching for more knowledge and improved skills to deal with illness, instead of blaming themselves for the misfortune. They also used a strategy of positive comparison (e.g. not being in the worst situation of all, in a better situation than other care-givers).

1. Reducing Expectations

- “As Chinese, we always said ‘If you are easily satisfied, you will always feel happy’. I am such a kind of person, I never expect too much.” (Mr. A)
- “I do not expect much from the young. They have their own career and younger generation to rear.” (Mrs. B)

2. Searching for Greater Knowledge and Skills

- “Whenever there were relevant talks and seminars, I would attend and learn how to take care of my wife”. (Mr. A)
“I tried my best to search for knowledge of the disease my husband was suffering, so that I know how to treat him better.” (Mrs. B)

3. Positive Comparison

“I am an optimistic person….you have to think more about happy things, to cheer yourself up. Say that there were many others who did not even have a wife” (Mr. A)

“If I am just thinking that his illness (Parkinson) will not get better, it is very miserable. But if I look at others whose situations were even worse, I am thankful that my husband can still be with me.” (Mrs. B)

4.4. An Explanatory Model of A Positive Care-giving Experience

Based on the above, a model of care-giving experience is postulated (figure 1). It is a model on how care-givers make sense of their caring experience and how care-giver meanings mediate the negative aspects (e.g. stress) of caring. Indeed, none of the two care-givers told us that they found the experience a happy one, but they would still stay on and could even have some positive things out of the process.

However, such an explanation only tells how a person cognitively cope with an experience which is not pleasant. It fails to account for questions such as ‘what if the care-giver’s own circumstances worsen, say physically deteriorated or income reduced?’, or ‘what if housing condition changes?’. The present model, as any cognitive model, downplays the importance of external circumstances such as social support and an environment conducive to care. Along this line of thinking, the contents of the interviews were re-searched again for indications of how the care-givers interpreted and interacted with external conditions.
4.4.1. External Conditions

The contents showed that there was a reality consideration for adverse effects and a conscious selection for positive reinforcement for sustaining the caring experience.

1. Reality Consideration

Both care-givers mentioned that they were very conscious of their own deteriorating ability to sustain the same level of care, but they would do what they could until they die. It was evident too the two care-givers were realistic in their choices: Mr. A refused an aged home placement for his wife (should they be taken in as a couple, he would have accepted) but accept extra help from the multi-services centre he was attending; Mrs. B hired a maid when she could not take care of her husband alone. Both were clear that when situation deteriorated, they might have to give up their care-giving roles.

2. Positive Reinforcement

The care-givers had a tendency to select events which had a positive reinforcement effect on sustaining care, the most often mentioned events were:

Reinforcement from the cared person

- responses (such as a smile or tears), verbal or non-verbal, from the cared persons to the care-giver was an immediate and essential element for sustaining the latter in the caring process
- signs for acceptance of care-giver’s care (e.g. non-rejection, cooperation)
improvement of (or maintenance of) the health status of the cared person would be a sufficient reward

**Recognition from others**
- others’ commenting that the caring tasks was difficult, and only the care-giver could have done them
- others’ acceptance, such as from relatives, friends and neighbours
- other care-givers’ complimenting what had been done by the person
- others’ recognition as a ‘role model’ in caring for the cared person

With this information, a fuller explanation can be proposed (see Figure 2).

**5. Conclusion**

The present study investigated two carers’ case histories to illustrate the pre-requisites of being good care-givers, the production of care-giving meaning and the justification of sustaining care. In connecting these processes, a model has been constructed to explain how and why care could be sustained. Clearly, the model is not exhaustive in including all possible elements of care-giving, but it formulates a basic frame of reference for the caring profession in bettering its work in sustaining informal care. The next stage is to test further this explanatory model with more carers and to introduce refinements to enhance its explanatory power.
### Table 1: Characteristics of the sample selected (N=2)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Care-giver A</th>
<th>Care-giver B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Age</td>
<td>83</td>
<td>65</td>
</tr>
<tr>
<td>Age of the cared</td>
<td>82</td>
<td>66</td>
</tr>
<tr>
<td>Frailty/disease of dependent person</td>
<td>- Stroke 3 times since 1991</td>
<td>- Parkinson’s Disease for over 10 years</td>
</tr>
<tr>
<td></td>
<td>- Frequent epilepsy</td>
<td>- Ryhice tube feeding</td>
</tr>
<tr>
<td></td>
<td>- non-ambulatory (wheel chair</td>
<td>- Non-ambulatory (totally bed-ridden)</td>
</tr>
<tr>
<td></td>
<td>bound)</td>
<td></td>
</tr>
<tr>
<td>Caring tasks</td>
<td>- Personal care (locomotion off</td>
<td>- Running errands, supervising care (employed a maid)</td>
</tr>
<tr>
<td></td>
<td>unit), cooking, marketing etc.</td>
<td>- Cooking, marketing etc.</td>
</tr>
<tr>
<td>Care hours</td>
<td>Whole day</td>
<td>Whole day</td>
</tr>
<tr>
<td>Years of caring for the person</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Education level</td>
<td>Secondary school in Mainland</td>
<td>University in Mainland</td>
</tr>
<tr>
<td>Income</td>
<td>Social Security payments</td>
<td>Own asset, good income</td>
</tr>
<tr>
<td>Family member</td>
<td>Nil in Hong Kong</td>
<td>1 daughter in HK recently; others emigrated abroad</td>
</tr>
<tr>
<td>Use of formal service (long-term care)</td>
<td>Nil</td>
<td>Nil</td>
</tr>
<tr>
<td></td>
<td>* wife previously offered a place</td>
<td>* husband previously offered a place in a Nursing home, but was not taken up.</td>
</tr>
<tr>
<td></td>
<td>in a C&amp;A home, but was not taken</td>
<td></td>
</tr>
<tr>
<td></td>
<td>up</td>
<td></td>
</tr>
<tr>
<td>Informal support</td>
<td>Nil</td>
<td>Employed a maid to assist in care</td>
</tr>
<tr>
<td>Religion</td>
<td>Christianity</td>
<td>Nil</td>
</tr>
</tbody>
</table>
**Figure 1: An Explanatory Model of Positive Caring Experience**

- **Meaning**
  - *Tough Personality* → never give up
  - *Reduced Expectations* → more easily satisfied with reality
  - *Knowledge seeking*
  - *Positive comparison*
  - *Commitment to a relationship*
  - *Care-giving ideology & belief*

- **Pre-caring Conditions**
  - Make sense of caring experience:
    - producing one’s own meaning

- **Care Justification**
  - Love & Friendship
  - Companionship
  - Gratification & satisfaction
  - Responsibility/Commitment
  - Personal Growth
Figure 2: Cycle of Positive Caring Experience

Pre-caring Conditions: tough personality, philosophy & religion

Make sense of care giving experience: rationalized via love, commitment, companionship etc.

Meanings produced and justified: growth, satisfaction, improved relation with the cared etc.

Behaviour reinforced by external conditions: Others’ praises, positive comparison, social support

Sustains Care-giver

Adjustments to reality conditions & selecting events for positive reinforcement
Appendix 2

References:


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History
The Asia-Pacific Institute of Ageing Studies (APIAS) was established as a University-wide institute in 1998 and has been operation as one of the research Centers in the Institute of Humanities and Social Science (IHSS) since September 2001. The gerontology and issues related to population ageing in Hong Kong and the Asia-Pacific region.

Our Mission
“To develop a better environment for older persons and their families in Hong Kong and the Asia-Pacific region.”

Our Objectives
➢ To assist in the strengthening of undergraduate, postgraduate and professional Training in areas related to health and welfare of older persons, demography and epidemiology
➢ To enhance knowledge, awareness and understanding of ageing in society Amongst students, professionals and the wider public
➢ To encourage cross-cultural research and co-operation on ageing in the Asia-Pacific region
➢ To offer research and consultancy services

For further information on APIAS and opportunities for research collaboration and affiliations with the Institute, please contact

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