(A) Title

What does co-morbidity and adherence to treatment regimen mean to elderly with differing level of physical dependency?

(B) Team members

No.	Name	Designation	Affiliation	Study role
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(C) Summary of study

Elderly are at risk of being non-adherent because they have complex treatment regimens and are usually prescribed with numerous medicines daily. Hence this study aims to provide insights on how these elderly with differing functional status view their multiple chronic illnesses and adhere to their treatment regimens so that interventions can be implemented to better support them in managing their multiple chronic illnesses.

This study adopted a descriptive phenomenological approach. Twelve participants, with varying degrees of physical dependency, were recruited from Medical Social Services in a local hospital through stratified sampling. Individual semi-structured interviews were conducted. The interviews were transcribed and thematically analysed.

Preliminary results showed that symptoms from the illnesses threatened the participants' sense of normative identity. Hence this affected how the participants viewed the treatment regimens, which could potentially be a possible source of hope for them to regain their functioning and meaning in life or a loss for them in term of the functional limitations they are presented with. Participants therefore would constantly evaluate and adjust these treatment regimens in their life such that these treatment regimens are congruent to their identity standard of hierarchy of salience, and to achieve a new normalcy.

The initial findings highlighted the importance of discussion of implications of illnesses and treatment regimens on self-identity as part of assessment when dealing with issue of non-adherence. This suggested that dealing with issue of non-adherence is beyond the financial aspect. There is a need to incorporate in our system where practitioners facilitate the conversation with older persons in establishing a new normative as an intervention.

(D) Aims of the study

This study aims to study the experiences of elderly patients with multiple chronic illnesses in adhering to their treatment regimens. The objective of this study is to seek to understand how elderly patients, with varying degree of physical dependency,:

1. View their multiple chronic illnesses and treatment regimens
2. Negotiate with their need for individualised treatment regimens

In this study, adherence is defined as "the extent to which a person's behaviour – taking medication, following a diet, or/and executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider" (World Health Organisation, 2013).

(E) Methods of Research and Progression

This study adopted a descriptive phenomenological approach. Participants were recruited through stratified sampling based on their degree of dependency using Shah's Modified Barthel Index (Shah, Vanclay & Cooper, 1989). The targeted sample size were twenty participants or more till saturation was met. However, there were only twelve participants recruited up to date. Face-to-face semi-structured interviews were conducted, and participants were asked to share their perspective on having multiple chronic illnesses, their views on their treatment regimens and their experience in managing their treatment regimens.

The interviews were transcribed and thematically analysed using Colaizzi's method of analysis. The interviews were analysed, using lens of identity theory (Burke & Stets, 2009). According to Burke et. al (2009), a person would assume multiple identities that were related to their roles and their meanings, which linked to the social structure. These social structures refer to the networks such as groups, organisations, community, where interactions and different roles took place. Identities are activated based on the hierarchy of salience. Identities, with higher commitment or prominence, are more likely be activated. When the self (identity) is verified and appraised, the sense of well-being was enhanced. When appraised situational meanings are not congruent to their identity standard, for instance in the situation of loss of identities, conflict of identities or change of identities, a person might experience distress and would also act in ways to achieve verify their identity or to alter their identity standard for a lower identity.

(F) Results of Research

As the study is still ongoing, therefore the results presented are preliminary findings. The participants interviewed were aged between 60 and 86. They were mostly single males and are independent in term of their physical functioning. Most of the participants were required to take at least seven to twelve pills per day.

Table 1: Demographic information of participants

Characteristics	Sample (n=12)
Age (Range)	71 years old (60 – 86 years old)
Sex	
Male	8
Female	4
Highest educational level	
No formal education	3
Primary and below	3
Secondary	2
O/N Level	3
ITE/CIDB	1
Housing type	
1/2 -room HDB flat	2
3/4/5-room HDB flat	9
Executive flat	1
Living arrangement	
Alone	5
With spouse	2
With children	2
With siblings	1
With others	2
Number of pills per day	
3 to 6 pills	1

7 to 12 pills	7
12 or more	4
Level of dependency (based on MBI)	
Independent	8
Dependency	4
Self-reported adherence	
Yes	2
No	10

There were three preliminary main themes that were found in this study. There were:

- Theme 1: Gradual loss of self-identity
- Theme 2: Appraising treatment regimens on identity
- Theme 3: Influence of social network on identity and treatment regimens
- Theme 4: Constructing a new normative identity

Theme 1: Gradual loss of self-identity

The participants experienced a loss of self-identity upon the onset of illnesses. This self-identity is lost gradually with the progression of illness or development of new illnesses. There were three sub-themes that formed this theme of gradual loss of self-identity.

Sub-theme 1: Illness attribution

Participants had differing views on what attributed to their co-morbidities, depending on their perceived level of control and responsibilities towards the co-morbidities. Some older adults assumed responsibilities by attributing to their poor choices and decisions made or other commitments that were of higher priorities, excluding health, during their younger days, thus leading to the complications of their illnesses. The verbatim below demonstrated how Participant 4 minimised the importance of medication-taking during his younger days, thus leading to current complications.

> *"The doctor told me that I had diabetes [when in my 30's]. But that time it was very slight because I only took half a pill only. So that time, I didn't care because just slight only."*
>
> *~ Participant 4 (68 y.o., Male, Chinese, Independent)*

Other participants saw the developments of co-morbidities and complications as a natural process of ageing. Some participants perceived the occurrence of co-morbidities as God's plan for them to deal with the implications raising from the co-morbidities.

Sub-theme 2: Symptoms as indicators in life

Symptoms were used by participants to determine the degree to which their illnesses were controlled and the effectiveness of the treatment regimens. Participants commonly used pain, breathlessness, swelling and tiredness as indicators to judge their state of conditions even when they had knowledge or lack of knowledge about their treatment regimens.

> *"I cannot drink too much water. Doctor tells me to restrict to one litre per day. But I take more than that because I feel that my legs are not swollen."*
>
> *~ Participant 4 (68 y.o. Male, Chinese, Independent)*

Participant 4 agreed that he did not strict adhere to the fluid restriction. Instead he took more when he used lower limb swelling as an indicator to determine the amount of fluid he took even though he was told of the fluid restriction.

"I don't know [how much water to take]. But I can feel one if [sic] if I drink too much…feel breathless and hard to walk"

~ Participant 6 (67 y.o., Female, Malay, Independent)

Participant 6 was a lady who did not have information about fluid restriction despite her background of chronic kidney disease. Hence she used breathlessness and swelling to determine her fluid intake that day.

Sub-theme 3: Multi-dimensional consequences of illnesses

Participants, who suffered from co-morbidities, experienced multi-faceted losses. These losses include loss of physical health due to deterioration of illnesses, financial means due to loss of employment and income, loss of social roles and even meaning in life.

Furthermore they also anticipated the potential losses and risks that raised from possible complications in their present health status. These participants were most concerned about having fall, stroke and dialysis as they perceived these illnesses as ones which would lead to losing more functional abilities and being a burden.

Theme 2: Appraising treatment regimens on self-identity

Participants were more likely to resist treatment regimens when it reinforced the loss of self-identity.

"I was worried as I would only be left with one leg. Both my wife and I were thinking on delaying the amputation. And we delayed for a long while, till the doctor said I could no longer delayed. My mobility…is over."

~ Participant 3 (66 y.o., Male, Chinese, dependent)

"The doctor told me that the kidney is not functioning and I need to consider doing dialysis. I told the doctor that I'll think about it but I'm not prepared to do it now…I'm prepared for anything when it comes, it comes. But not like…now."

~ Participant 1 (79 y.o., Male, Chinese, independent)

Participants were more likely to adhere to treatment regimens when the treatment regimens helped in preserving the remaining normative identity by delaying more undesirable consequences.

"What can I do, right or not?" I should have controlled myself last time. It is already too late. But still [sic], there is still hope that you try to delay [dialysis] as long as possible."

~ Participant 4 (68 y.o., Male, Chinese, Independent)

Participant 4 started to take his medicine more regularly after witnessing the impacts of dialysis on other patients as he wished to delay dialysis as long as possible.

Similarly other participants were more likely to adhere to treatment regimens if the treatment regimens helped in re-establishing their self-identity so that they could regain their independence and resume their social roles. Hence Participant 2 agreed to surgery so that he could return to workforcec.

"If the surgery is successful, I should be able to stand longer and I want to work. Work is a source of comfort. You will become useless if you don't work"

~ Participant 2 (67 y.o., Male, Chinese, Independent)

Theme 3: Interaction between social network and treatment regimens
Participants' social network has a role in influencing the decisions that the participants undertook pertaining to treatment regimens. Their social circumstances, such as the level of support and roles and responsibilities, were one of the factors that influence their decision-making. They were more willing to consider adhering to treatment regimens when it allowed them to continue their respective roles and responsibilities that they had, for instance as a caregiver.

The people in their circle of influence, which included their families, neighbours and fellow patients, were active players in participants lives as they exchanged their treatment experiences and alternative treatment regimens. One participant recounted the conversations that he had with other patients during his visit to the dialysis centre made him adhere to his treatment regimens more closely so that he could delay the need for dialysis, which he perceived to have affect his self-identity.

Relationship with healthcare professionals is a key factor which will influence the participants' decision-making. Most of the participants trusted the healthcare professionals, especially the doctors. They were more willing to adhere to treatment regimens when the healthcare professionals took time to explain their conditions and treatment regimens as this provided the participants a sense of assurance.

Theme 4: Constructing a new normative identity

Sub-theme 1: Experimenting and adjusting to changes
Participants were constantly evaluating and experimenting treatment regimens on the symptoms of their co-morbidities and their psychosocial circumstances. Simultaneously they were adjusting the treatment regimens based on the effects on their symptoms and impacts from their psychosocial circumstances. When the treatment regimens are consistent to their belief and values in life, they would integrate into their lifestyle to form a new normative identity.

Sub-theme 2: Dealing with emotional reactions
Participants were oscillating between grief with emotions such as regrets, disappointment and acceptance. They coped by using problem-focused strategies such as making the necessary lifestyle changes or emotion-focused strategies such as avoidance or distraction as they worked towards constructing a new normative identity. In this study, finding an employment became a source of comfort for some participants so that they could engage in a more meaningful life. Participant 4 mentioned about how working could keep him engaged.

> *"Of course, I want to work. Who don't want to work? At least you can pass your time and get some income. Furthermore, it keeps my mind active…if I can get a part-time job, I can talk to other people in the meantime…then I won't find it boring"*
>
> *~ Participant 4 (68 y.o., M., Chinese, Independent)*

(G) Future areas to take note, and Going Forward
The preliminary results showed that participants' self-identity was threatened as symptoms, instead of diagnosis, became an important indicator in their lives. They would try to negotiate their treatment regimens in order to achieve normalcy, so that they could construct a new normative identity. As a practitioner, this suggests the importance of role identities and implications of illnesses as part of assessment when dealing with issue of non-adherence.

Practitioners will likely need to facilitate the conversation with older persons in establishing a new normative as an intervention.

At a policy level, this study suggests that provision of financial subsidy is unlikely adequate in addressing the issue of non-adherence. This study suggests a need to create systems and space that allow older persons to discuss the issue of self-identity in order to deal with the issue of non-adherence. This will spell the need to change the way healthcare systems are designed such that older persons' perspectives are incorporated as a form of intervention.

As the results presented were preliminary, more data collection and analysis are still required to understand the older persons' perspective on adhering to treatment regimens. These findings will be helpful in designing and implementing intervention to better support this group of older persons in managing their multiple chronic illnesses. It is also hoped that findings will also lead to the development of a localised model of adherence in guiding our local practice.

(H) Means of Official Announcement of Research Results

The team aims to present the research findings at the "2020 World Social Work Conference", which is held in Calgary in Canada in 2020, and in the journal of "Health Expectations"