Supplemental material

Title: Vignettes probe questions
Description: Set of vignettes probe questions

- What medical profession would be most likely to provide a diagnosis?
- What profession would most likely support Mr./Mrs. X with his/her needs after a diagnosis?
- What family arrangements would likely be made (and how this may affect the caregiver(s))?
- Where would family members likely turn to in order to receive advice and support?
- Who would likely be the main (unpaid family) caregiver?
- What other care and social support may be available for people with dementia and their carers (paid carers, church groups, voluntary groups, state services, live-in (migrant) carers)?
    - How would families access this support?
    - Would families be likely to accept available services?
    - Can families afford these services?
- Would the person with dementia and his/her family be likely to experience stigma?

Title: Case Vignettes
Description: Complete vignettes

Vignette 1

Mrs. Amélia is in her 70s and lives with her husband in a small village in rural Brazil. Mrs. Amelia's daughter and her family live nearby. Over the last year her family has become increasingly worried about Mrs. Amelia, as she keeps losing things and puts items into odd places. A friend has told the daughter that Mrs. Amelia had been wondering in the village and seemed a bit lost. The daughter is worried about what people may think or say about and how they may react to her mother. Mrs. Amelia used to have a very neat house and looked after her appearance. She also helped her daughter with the children. Over the last few months Mrs. Amelia seems to be no longer interested in these things. Mother and daughter used to have a good relationship, but recently there have been a number or arguments. The daughter is thinking of taking Mrs. Amelia to the community health center, but she knows that her mother does not like to go there.

Even though Mrs. Amelia does not like to go to the community health center (primary care unit), her daughter would try to convince her to make an appointment with a doctor. Possibly, she would take her mother to a traditional healer before taking her to a doctor. Given her mother's reluctance to go to the community health center, it is likely that being seen by a traditional healer would be more well accepted by Mrs. Amelia. Another possibility would be that Mrs. Amelia's daughter and family would think Mrs. Amelia's strange behavior was part of a natural ageing process, so no further action would be taken to investigate her condition. However, supposing that an appointment with a doctor had been made, the consultation could happen in a primary care unit with or without the Family Health Strategy Program, depending on where they live.

The Family Health Strategy is the cornerstone of the primary healthcare system in Brazil, the program aims to expand, qualify and consolidate the delivery of healthcare to the population according to the precepts of SUS and involves healthcare teams that delivery person-centered care in the communities. The program currently covers about 62% of the Brazilian population. It is possible that after the first consultation with a GP, Mrs. Amelia would be referred to a specialist (neurologist, geriatrician or psychiatrist) who would establish or not the diagnosis of dementia. Not all doctors are well trained to diagnose dementia in Brazil.

A less likely possibility in a small village, would be that her family would take her to a private doctor (out of pocket or private insurance) in a big city. However, this would require more family support such as dealing with logistics, travel costs, consultation costs, etc. Her daughter would likely be the person taking on this role.

Assuming Mrs. Amelia had been diagnosed and had access to a family health team, the doctor would probably say to Mrs. Amelia's family that Mrs. Amelia has memory issues and that these are a 'normal' part of ageing, even though a medication that is specific for dementia would likely be prescribed. Mrs. Amelia would probably have access to her medication free of charge via SUS (the Brazil's Universal Health System) even if the consultation was with a private doctor. However, it might happen that for getting the medication free of charge, Mrs. Amelia's daughter would need to travel to a health unit located in a larger city. It is likely that the doctor who gave her the diagnosis, as well as the family health team, would become the key professionals to support Mrs. Amelia with her needs.

Besides, she would make use of clinical services from the secondary level of care too. However, Mrs. Amelia or her family would not likely be referred to any psychosocial advice or support services in the community. As a note, it is possible that by the time Mrs. Amelia had finally been diagnosed with dementia, her symptoms would have worsened and she would probably be in a more advanced stage of the disease.

As Mrs. Amelia lives with her husband and nearby her daughter, this living arrangement is likely to be kept for a while until Mrs. Amelia and her husband's independence start to be compromised. In such a case, her daughter would progressively become the main caregiver for Mrs. Amelia, meaning she would probably end up leaving her job at some point to take care of her mother. This situation could bring financial constrains to the life of Mrs. Amelia's daughter as there is no payment cash transference by the government for informal/familiar caregiver in Brazil.

Unfortunately, it is likely that family members would not have enough information regarding dementia and so would probably not get involved with supporting Mrs. Amelia and her daughter. Information and emotional support for people with dementia and their carers can be delivered free of charge by NGOs, but these associations are not common in rural areas or even in urban areas. Thus, many people lack this kind of support and feel themselves even more burdened. People generally access the NGO services when they are "luck enough" to be told about the existence of them or when they discover the associations through searches in the internet. Public health campaigns are also meant to deliver information and support on dementia, but these campaigns are rare too.

Stigma is frequently experienced by people living with dementia and their family/carers in Brazil. Stigma can be specially observed in rural Brazil where, generally, not enough information on dementia is available. People tend to face the disease as a normal stage of ageing or as madness and there is a sense that nothing can be done for the person living with dementia and her family. Mrs. Amelia's daughter would probably notice that friends and family members would gradually stop visiting them and would not use the term "dementia" to refer to her mother's health condition. On the other hand, in a rural area people generally know each other and a sense of welcome and empathy might be built, resulting in less stigma and more support to Mrs. Amelia and her family.

Vignette 2:

Mrs. Beatriz is in her 70s and lives in mid-size town in Brazil. When her son got married, she moved in with her son and his wife. For the last few years, she helped the family by looking after the grandchildren and doing housework and cooking while her children were working in the business they own. About two years ago, Mrs. Beatriz's family became worried about her behavior and memory. Now Mrs. Beatriz mostly stays at home. She does not go out unless someone of the family accompanies her. Mrs. Beatriz also stopped cooking, which she always enjoyed. Her daughter-in-law reminds her to take medication she needs for other health issues and helps with dressing. Mrs. Beatriz does not like being left alone in the house. Mrs. Beatriz's daughter-in-law is worried about her hygiene, but having to look after the business, taking over the cooking and shopping for the family as well as making sure that Mrs. Beatriz is safe and well during the day takes a lot of her energy and so she postpones thinking about this aspect. Once a week Mrs. Beatriz's son takes his mother to [church].

It has been two years since Mrs. Beatriz changed behavior and has not been taken to a doctor. This means she might have never been taken to a consultation and, as the disease progresses, her nuclear family would just try to adapt themselves to the situation, somehow sharing Mrs. Beatriz's care needs between them, but without expecting any support from the community or extended family. However, there is still a chance her family would take Mrs. Beatriz to a free consultation with a general practitioner (GP) who is part of the SUS (universal health system) or would take her to be consulted with a private doctor (out of pocket or institution private insurance). In any of the cases, Mrs. Beatriz could be diagnosed or not, as many doctors still have no special training in dementia, even in mid-size towns in Brazil. Therefore, she might have received the diagnosis with some delay.

After being properly diagnosed with dementia, Mrs. Beatriz would be prescribed medication that is accessible free of charge via SUS at the point of access. Although SUS offers non-medical treatment such as physiotherapy, phono audiology etc. it is unlikely she would be referred to these treatments given a possible lack of knowledge by doctors (for instance) that might not associate these treatments with helping people living with dementia. Mrs. Beatriz could also have access to therapies through healthcare insurance or paying for them privately.

If Mrs. Beatriz lives in a region covered by the family health strategy, some professionals such as doctors, nurses, dentists, physiotherapists and community health workers could provide information and sporadic support (e.g. home visits once a month to follow up on specific issues) to Mrs. Beatriz, however the government would not provide her with formal carers or any other human resources for the day-to-day care. Unless Mrs. Beatriz's family decided and managed to get one of the few places in a long-term care facility (probably a philanthropic or private one as the public ones are nearly non-existent), Mrs. Beatriz would probably continue to live at her son's house for a long time.

Mrs. Beatriz's wider family could give some sporadic help, but normally, the day-to-day chores and care would be provided by her nuclear family (mainly by her daughter-in-law). Mrs. Beatriz's limiting condition would increase her family's worry regarding her health and would require more time spent to meet her caring needs, resulting in a more stressful routine to Mrs. Beatriz's daughter-in-law and less time dedicated to the family business. As time goes by, Mrs. Beatriz's daughter-in-law would probably have to reduce her activities in the family business to spend more time caring for Mrs. Beatriz and the house. This could restrict the family income as there is no payment cash transference program in such cases by the government. Another option would be to pay for a caregiver for Mrs. Beatriz so that her daughter-in-law would not be at risk of stopping to work in the family business. However, paying for a caregiver can be very expensive in Brazil and Mrs. Beatriz's family probably would not be able to afford it.

Although it is not a regular behavior from family members in Brazil, Mrs. Beatriz's family members could get advice about dementia through some older people's association, family health strategy team or community health centers (as they might exist in the town). Some of these services could be accessed free of charge through SUS. It is possible that Mrs. Beatriz and her family would experience stigma and lack of support from their friends and other family members. It is likely that Mrs. Beatriz's nuclear family would be judge by other family members in case they decided to move Mrs. Beatriz to a long-term care facility. Not much support would be available from their relatives regarding daily care tasks, as they might feel impatient when dealing with Mrs. Beatriz.

Vignette 3:

About five years ago Mrs. Claudia started to become forgetful. Now, 75 years old, Mrs. Claudia hardly ever leaves her room in her daughter's house where she was moved when it became clear that she could no longer look after herself. The daughter and her granddaughter help her with dressing, eating, washing and going to the bathroom. The family has to make sure that food is not too chunky as Mrs. Claudia has difficulty swallowing. It is difficult for the daughter's family to go away together for the day as someone always needs to be around to look after her. The constant care needs in addition to her own family responsibilities also pose a strain on Mrs. Claudia's daughter has her own health issues. Mrs. Claudia's other children visit during holidays but find it difficult as she cannot always remember who they are.

Mrs. Claudia may or may not be taken by her family to a public health doctor, a private doctor, or a doctor from a health insurance for assessment and diagnosis. In some cases, such as Mrs. Claudia, the family may think the symptoms are a normal part of ageing and will look after her needs as these appear, never taking her to a clinician for a proper assessment. In some cases, medical doctors may also not be prepared to diagnose or may also think this is a normal 'senile issue', and so Mrs. Claudia would stay without a diagnosis. This situation could result in poor care and support to Mrs. Claudia and could cause family disarrangements due to lack of understanding about the dementia symptoms.

In Brazil, the delivery of health is organized in three levels of care: the primary care level – that is the gateway for accessing SUS, promoting education, evaluation and disease-risk reduction among families –, the secondary level of care which includes specialist care services, and the tertiary level of care which includes high-complexity procedures and hospitals. If the primary level health care doctor suspected dementia, Mrs. Claudia would then be referred to the secondary level healthcare team (neurologist, psychiatrist or geriatrician) to establish diagnosis (with extra exams if needed) and pharmacological treatment. If these specialists are well trained for this, Mrs. Claudia would then receive a diagnosis, pharmacological treatment, and would continue to be assessed periodically by the secondary care team.

Mrs. Claudia's family (as well as neighbors and friends, if any) will likely to be the only source of support available for Mrs. Claudia, both financially (if Mrs. Claudia income is insufficient to pay for her own needs) and on the day-to-day-care, unless they can pay for care services privately. A few branches of the Alzheimer's Associations exist around the country which can provide information and emotional support; however, as a standard rule, no support is available freely with regards to the physical care or respite services for carers. Only a few care homes are available through government and religious associations around the country, meaning that Mrs. Claudia is likely to continue to be cared for at her family home until the end of her life.

There are home care services provided by the public health system, however very often these only include visits from professionals regarding healthcare/medical needs and not the care itself (feeding, bathing, etc.). If Mrs. Claudia's family lives in an area covered by the family health strategy, the team might provide some help with specific care needs in advanced stages of dementia, such as in case the person is using a feeding tube or in case of pressure injury or other would dressing. The care provided by families is fully unpaid and there are no allowances for family carers. Mrs. Claudia would likely have a retirement pension and disability allowance could be provided in some cases.

The public health system offers health-care-related supplies in some cases (diapers, feeding tubes and enteral diet, materials for dressing wounds) and dementia medication is available freely through the SUS. Private services are expensive, mainstream private insurance usually do not cover continuous formal care, and dementia training is not common practice, meaning that the care received would probably not be 'dementia friendly'. People with dementia do experience stigma and are often disempowered. Lack of knowledge and awareness about dementia lead to late diagnosis, when people with dementia would no longer be capable of making decisions regarding their own care. Mrs. Claudia's daughter would probably be very unsupported by her own family and employer, which would probably make her quit her job, furthering the financial strains on the family. The absence of a systematized support system to support carers makes it likely that Mrs. Claudia's daughter would also face stressful events and personal problems in her relationship with her own daughter given the restricted time they have to relax and enjoy each other's company. It is unlikely that the family will have the option to put Mrs. Claudia in a care home, but if this become a possibility, it is likely that they will be judged by her own family and friends.

Vignette 4:

Mr. Diego lives by himself in a mid-size town in Brazil since his wife passed away last year. His children have moved to the bigger city to work and can only visit once a month. Over the last few months Mr. Diego has found it more difficult to look after the house and himself. His son noticed that his father does not seem himself and is worried about him and what people may think if they see his father.

Mr. Diego would be entitled to a consultation with the general practitioner (medic) through SUS which provides universal healthcare that is free at point of access. However, it is unlikely that Mr. Diego would see a doctor by himself, he would need one of his children to take him to a medic consultation (regardless of being a consultation by the public or private health sector). Even in mid-size towns, general practitioners often do not have enough knowledge to diagnose dementia, so Mr. Diego could be at a later stage of dementia when diagnosis would formally be given (if any).

Mr. Diego would need to move in with his son or another family member to be assisted with his daily activities as no continuous care or support would be available for him at his own residence, unless he paid for it privately or via health insurance (the latter usually do not include day-to-day care).

Primary healthcare teams would provide visits for specific health needs, but long-term further care would need to be provided for by the family or privately. It is possible that in one of these visits, the primary care team would make a multidimensional assessment (to have a biopsychosocial diagnosis of Mr. Diego and identify his frailties) and develop a care plan to be performed together with his family. However, although this service is available, its implementation will depend a lot on the knowledge of the health team. Mr. Diego would probably become socially isolated and would not be encouraged to be independent.

It is very likely that Mr. Diego would experience stigma from neighbors or even from some family members as he could be excluded from meetings given to a possible “not socially accepted” behavior. His son is already worried about what people may think of his father. Friends and neighbors may not be supportive and could judge Mr. Diego’s family for leaving him living at his own house, or in case they decided to pay for a long-term residential care home. Probably, a daughter or daughter-in-law would take responsibility over his care taking him to live with her and her family or moving in his house.

Vignette 5:

Mr. Elias has left his family many years ago to work in Curitiba in Brazil. While he visited his family once a year, his children have become increasingly estranged and he has lost contact with them after his wife passed away five years ago. He lives on his own in a small flat. Mr. Elias finds it difficult to find his way to the shops and back, has difficulty remembering appointments and often forgets about eating.

Mr. Elias’s work colleagues, company’s human resources sector, neighbors and friends, if any, would possibly be the ones to refer him to a consultation with a doctor at the public health system. It would take a while before Mr. Elias realized he himself would need an appointment to discuss his condition. After multiple appointments and a series of tests, he would probably be told not to worry about being forgetful and would be prescribed tablets to release the stress and depression of living alone.

Because many general practitioners often see dementia as a normal part of ageing, it is likely that Mr. Elias would be at a later stage of dementia when diagnosis would formally be given. At this stage, his safety would be compromised and his capacity to plan his own future would be diminished.

Although Mr. Elias's work colleagues, neighbors and close friends (if any) could ask for advice and support through Alzheimer's associations based in Curitiba or through online courses (some of them are paid ones), this scenario is not likely to happen as there is not enough information about these services for people in Brazil.

Because there is no dementia-specific policy in Brazil, as well as limited access to free care homes, Mr. Elias would probably need primary care health professionals to refer him to social workers in order to either remediate his relationship with his family or to be placed in a public long-term care facility.

Although it is a less likely possibility, Mr. Elias could try to contact one of his children. After knowing the health state of their dad, perhaps one of his children could ask Mr. Elias to live with one of them (in Brazil there is a tacit belief that children must support their older parents, besides this responsibility is also stated in the Brazilian Federal Constitution) or convince him to go to a public long-term care facility in his hometown to be closer to their children (this possibility, however, may not exist). Another possibility would be Mr. Elias to be oriented to pay for a caregiver for himself, depending on his financial situation. Nonetheless, somebody would have to help him to deal with work regulations as his capacity diminishes with the progress of the disease.

Mr. Elias could experience stigma as people in the neighborhood would probably start to note his different behavior and could start to label and judge him and his family, in a way they would not be aware of. Unfortunately, the lack of information about dementia in the community may result in a lack of support from people in society.

Vignette 6:

Mrs. Fátima is in her late 70s and lives with her daughter's family in a riverside community located in a remote area in the midst of the Amazon forest, in Brazil. They all live together in the same small wood made house. Mrs. Fátima is descendant of the Tikuna indigenous tribe, with restricted Portuguese knowledge or fluency. Mrs. Fátima is well respected in her community as she has tried to keep her tribe's culture 'alive' over the years. Mrs. Fátima has become increasingly withdrawn and has stayed alone inside her house most days in the past months. Her daughter is concerned as Mrs. Fátima has been having visual hallucinations, has become aggressive towards her small grandchildren, and has been forgetful. People who have been in her house have spread the news around the community that she is becoming 'possessed' with malevolent spirits. Mrs. Fátima's family has consequently tried to keep Mrs. Fátima inside their house as much as possible, which has made her even more unwell. Her daughter has started to give her traditional herbal infusion hoping to calm Mrs. Fátima down. The city's family health team visits the community once a month by boat, but Mrs. Fátima's daughter fears that her mother will not accept help and so she has postponed/avoided talking to the health team about this.

Mrs. Fátima would be entitled to a consultation with the general practitioner (medic) through the public health system which provides universal healthcare that is free at point of access. However, general practitioners often do not have enough knowledge to diagnose dementia. In a remote setting such as the Amazon forest, the health priorities are likely to differ from a large Urban area, and health issues such as malaria, diarrhea, and undernutrition, are likely to be prioritized over chronic conditions affecting older people. This is also partly due to the much smaller population of older people living in these communities.

Mrs. Fátima's daughter would have difficulty in discussing her mother's symptoms with the health care team due to language barrier and lack of understanding about what was exactly happening with her mom, which would probably lead to a deterioration of Mrs. Fátima's health and wellbeing before any action could be taken by the health team, and this would delay the diagnosis considerably. Other symptoms of dementia, apart from hallucinations and aggressiveness, could not even been noted by Mrs. Fátima's family given the lack of information about the condition. If the health team were actioned and suspected dementia, Mrs. Fátima and her daughter would need to travel by boat to a large city (such as Manaus) to go under further examination and tests. Several months would past and several trips to the big city would be necessary for Mrs. Fátima to be diagnosed. If a diagnosis were made, the medication could be brought to Mrs. Fátima via the healthcare workers on their monthly visits. However, Mrs. Fátima would be unlikely to have access to psychosocial support or formal care mainly due to the remote area she lives in.

Mrs. Fátima's daughter would slowly become her fulltime carer, and probably little training and information would be available for her. Even if Mrs. Fátima's family could pay for the long-term care, which would probably not be the case, service providers would not be available for her at the community she lives in. Mrs. Fátima would probably become more isolated as the disease progressed, and that would be both encouraged and accepted (as a sign of respect) by her family. Other senior tribe members would try to 'cure' Mrs. Fátima with natural medicines and other healing practices, which would make Mrs. Fátima more anxious and angrier. Though Mrs. Fátima is highly respected in her community, people could be afraid of her behavior due to the belief that this was caused by malevolent spirits. However, another possibility would be that people in the community would take care of Mrs. Fátima and supervise her when she was walking around the community. This could minimize the chance of Mrs. Fátima getting lost and contribute to keep her independence as she could go to the river to wash her belongings, for example.

Vignette 7:

Mr. Gabriel is in his late 60s, is from a Black ethnic group, and lives with his son's family at the top of an urban slum ('favela') in Rio de Janeiro, Brazil. Mr. Gabriel has diabetes, and is insulin dependent. He also has hypertension, arthritis, and chronic pain. Due to all these health issues, Mr. Gabriel has increasingly avoided going down the favela hill as the streets are tortuous and have led Mr. Gabriel to fall several times in the past. The high levels of violence also prevents Mr. Gabriel from getting out and about as he has lost a son during a shooting. Mr. Gabriel stays most days on his own as his son/daughter-in-law are working and his grandchildren are in school. Mr. Gabriel feels as if he is a burden to his family, so he tries to avoid 'complaining' to them about his health needs. He has been feeling different recently, with mood swings, memory lapses, and dizziness. He is really scared about what could happen to him, which has made him feel really upset and lonely for several weeks already.

Mr. Gabriel would probably continue in this situation for a little while and his symptoms would be faced as normal part of ageing until his son or daughter-in-law noticed something that called their attention, such as serious memory loss (e.g. forgetting the oven on). Mr. Gabriel's several health issues would likely mask his dementia symptoms and professionals would probably say that his symptoms are due to side effects of the medication in use or to his blood sugar levels.

Healthcare provision is free of charge at the point of use, and family visits are commonly provided by the primary healthcare teams. However due to the difficulty in access, the community healthcare team would tend to visit less often that area and the communication between Mr. Gabriel and his GP would probably be made through his son, who would likely be busy working full time in the city. Mr. Gabriel's son or his daughter-in-law would also collect his medication monthly free of charge at the primary healthcare unit.

Once Mr. Gabriel's family or health team noticed his symptoms, Mr. Gabriel would be taken for an appointment with the GP at the health centre, or a community health agent would arrange a visit of the family health team, where Mr. Gabriel would be examined. If the GP suspected of dementia, Mr. Gabriel would then be referred to a specialist as part of the secondary care system. Several months are likely to pass before Mr. Gabriel can be assessed by the specialist, who would do the neuropsychological assessment and would ask for further exams. The entire process to diagnosis is likely to take over a year. During this period, Mr. Gabriel is likely to be "supervised" by a neighbor in the absence of his family. Another possibility is that his daughter in law may decide to quit her job to stay with Mr. Gabriel. Nonetheless, this might not be an option due to the financial burden this decision could pose on her family, so it is likely that Mr. Gabriel's care would depend on neighbors or more distant family members or he would be left to his own care.

When Mr. Gabriel received his diagnosis (if any), they would access any specific medication free of charge through the "high-cost medication system", which requires several documents and exams in order to have access. In terms of non-medical treatment, it is likely that he would not have access to any, given the believe that his symptoms were consequence from the natural ageing process.

Due to his difficulty in getting out and about outside his house, Mr. Gabriel would likely continue to be isolated in his own community, and his dementia and other co-morbidities would deteriorate quite fast. Another possibility is that the family health team would visit Mr. Gabriel once a month, but the focus of the consultation would be his symptoms, medication, and physical care, with little support or information on the psychosocial aspects of his daily life.

Mr. Gabriel would probably be cared for by his daughter-in-law until his death, through which time he would be on and off the hospital for several infections and other health issues. As Mr. Gabriel became more and more dependent, the health team would decide (without the family involvement in the decision process) to use a feeding tube to feed Mr. Gabriel. He would also be using diaper quite early in the process, which would increase his risks for UTI infection. The diapers would be provided to Mr. Gabriel free of charge by the SUS.

The family finances would become deeply affected by Mr. Gabriel daughter-in-law's possible unemployment and Mr. Gabriel's care costs. She would face a lot of the complex health needs of Mr. Gabriel with very little support (if any). She would become depressed and would probably not look after her own health during the period she provided care to her father-in-law.

Vignette 8:

Mr. Hugo is in his late 60s, is from a White ethnic group, and lives with his wife in a large middle-class condo in Rio de Janeiro, Brazil. Mr. Hugo is a respected business administrator and still works every day. The company employees have been commenting about Mr. Hugo "strange behavior" and have spoken to the HR department about it. The HR demanded Mr. Hugo to take sick leave against his will, which really affected Mr. Hugo's confidence. His wife is concerned and has tried to convince Mr. Hugo to book an appointment with his doctor, however Mr. Hugo does not believe there is anything wrong with himself. He has got lost several times while driving his car, for which the police has been actioned once. He is now in risk of losing his driving license and Mr. Hugo's family is worried about his mental wellbeing, as well as his safety.

Mr. Hugo has a private health insurance and have regular health checks with his geriatrician. Once his wife convinced Mr. Hugo to go for an appointment with his geriatrician, they would easily be able to book an appointment for the next week or so. The clinic he normally goes is close by and Mr. Hugo and his wife can go by car. The geriatrician would do a neuropsychiatric assessment and would refer Mr. Hugo for further exams, such as a CT scan. Mr. Hugo would not need to wait very long for these, and if so, he would be able to pay for it privately. In few weeks or months Mr. Hugo would return to his doctor and a diagnosis would be given. Another possibility is that because of his reluctance in seeing a doctor, by the time Mr. Hugo had finally accepted to seek a consultation, his dementia symptoms would have advanced.

His doctor would say that his symptoms are a typical problem with older adults and that he should just go home, live his life as usual, and "follow up" from time to time. However, he would forbit Mr. Hugo from driving. Mr. Hugo would become depressed and would have trouble to make sense of his condition.

His wife would try to do everything for him, which would make him feel even more incapable. After taking the doctor's letter to the Human Resource (HR) Department at his place of employment/work, Mr. Hugo would be "invited" to take an early retirement. As Mr. Hugo became more dependent, the housemaid would become to help him with his daily tasks more and more. Mr. Hugo's wife would try and hire a home care worker, to which Mr. Hugo would probably be resistant to.

At some point Mr. Hugo cannot decide for himself anymore, and home care workers (paid for by the family) would come and stay full time caring for Mr. Hugo. He would only go to his geriatrician/psychiatrist only once in a while for to adjust his medication. As Mrs. Hugo's dementia advanced, the domiciliary healthcare team would start visiting him for nursing, nutritionist, and physiotherapist care and assessments. All the care, however, is very focused on Mr. Hugo physical care needs, and little about promoting his independence.

Mr. Hugo's children rarely visit and people they knew stopped visiting. His wife is retired and has her own health issues. She feels very isolated and miss having more intimacy with her husband as her house appears to have become a hospital – full of health professionals coming and going, hospital bed, diapers, etc. She is suffering from anticipated grief and she misses the husband she once knew. They had many dreams for their retirement, but now she feels like she's lost all of that. She feels that she is expected to cope and feels very lonely. However, the domiciliary care team or doctors have never asked her how she feels or what her needs are. In addition to that, they live in a house with stairs and she is faced with the decision of moving somewhere else so that her husband can leave their bedroom. Even with all these difficulties and feelings, Mr. Hugo's wife has never considered moving him to a residential as these institutions are very stigmatized in Brazil.

Vignette 9:

Mrs. Silvia is in her late 70s, is from a Mixed-Race ethnic group ("pardo"), and lives in a remote rural area in Aquidauana city, state of Mato Grosso do Sul, Brazil. Mrs. Silvia is the maid of the large cattle farm owner and has lived with her family in a small cottage in that farm all her life. Mrs. Silvia has always been really active and never felt the need to have health checks. Recently, Mrs. Silvia has suffered a stroke, which has affected all her day-to-day activities and has led Mrs. Silvia to develop memory impairment. Mrs. Silvia's increasing health needs has forced her daughter to quit her job and move in with her mother to provide full time care. Mrs. Silvia depends on the public health service for all her health needs, and this is located within 20km distance by car. Her daughter has been extremely stressed and tired as she feels totally unsupported. She feels impatient with her mother and has used of physical restrains to contain her mom's movements so that she can do the housework.

Mrs. Silvia would probably already be linked to the secondary care system (in the urban area) due to her previous stroke. Her daughter would bring the memory symptoms up during one of her appointments and the neurologist would probably be trained to suspect dementia. Mrs. Silvia and her daughter would have to do several trips to the main city for the clinical investigation, for which the farm owners would take her, or the municipality would send an adapted car through the social care system whenever she had an appointment, or Mrs. Silvia or the farm owners would pay for a taxi privately.

The diagnosis is likely to take several months due to the need to wait for CT scans and other tests. Mrs. Silvia would probably be prescribed anti-psychotic medication or another sedative medicine so she could be 'easier to handle'. Mrs. Silvia's daughter might have access to carers' groups at the outpatient clinic, but that is not a mainstream service, so one of her main unmet needs would be information about dementia and care. Besides, even if she had access to a carers' group, living in a remote rural area could prevent her of participating in such activities. Depending on the distance from the house, the primary healthcare team would visit Mrs. Silvia every so often to check on her situation. These visits would probably be focused on the physical and clinical needs of Mrs. Silvia, rather than supporting Mrs. Silvia's daughter with the care.

Mrs. Silvia and her daughter could receive financial support from the farm owner or not. Mrs. Silvia daughter would be entitled to disability allowance. They would be entitled to receiving diapers, wound dressing materials, medicines, and skin care. Due to the long distance to the city, it is possible that no private care provider would accept to provide care services at the farm, and all the care responsibilities would indeed fall on Mrs. Silvia daughter's shoulder. Mrs. Silvia's other male children would not help with the care.

Mrs. Silvia would be hospitalized several times throughout the years due to complications of dysphagia and diaper use (e.g. pneumonia; UTI). As Mrs. Silvia became more and more dependent, the health team would decide (without the family involvement in the decision process) to use a feeding tube to feed Mrs. Silvia. This would further increase the complexity of Mrs. Silvia's care needs, as well as her daughter's anxiety levels and poor sleep quality. Mrs. Silvia would become less mobile and would likely develop ulcer pressures due to lack of training and equipment to prevent them.

Vignette 10:

Mrs. Jaqueline is in her late 70s, is from a White ethnic group, and lives in a rural area in a remote part of Aquidauana city, in the state of Mato Grosso do Sul, Brazil. Mrs. Jaqueline and her husband own a large cattle farm and have several employees living in little cottages around the large property. Mrs. Jaqueline has always been really active and never felt the need to have health checks. Recently, Mrs. Jaqueline has suffered a stroke, which has affected all her day-to-day activities and has led Mrs. Jaqueline to develop memory impairment. Mrs. Jaqueline paid for all her care and exams privately and could pay for LTC services, however they live very far away from the main city and no service provider covers that area. Mrs. Jaqueline's increasing health needs has forced her husband to stay at home to provide care, which has made him extremely stressed and tired as he feels totally unsupported. He is in his late 80s and is also struggling with his own health issues. Their two children live in other states and cannot come visit them easily.

Mrs. Jaqueline would probably be linked to a neurologist due to her previous stroke and her husband would be able to contact him\her directly to ask for an immediate home-based private consultation. The neurologist would provide a thorough assessment and would ask for exams. Mrs. Jaqueline and her husband would go to the main city with their driver to undergo further examination privately, which would be much faster than the mainstream care (public or via insurance). The neurologist would then diagnose Mrs. Jaqueline and would prescribe medication, which Mrs. Jaqueline's husband would purchase in a local pharmacy monthly.

The neurologist would or would not refer Mrs. Jaqueline to other health professionals, such as a nutritionist or a nurse, for which they would pay privately. Mrs. Jaqueline's husband would ask for a few of his female employees from the farm to begin support him with the house chores and direct care with Mrs. Jaqueline, however they would likely not receive any training for that. The professionals who Mrs. Jaqueline’s husband hired for private consultations would occasionally assist with specific training needs they may have.

Title: Care pathways in the public and private systems for people living with dementia in Brazil