INTERACTIONS BETWEEN PATIENT AND CARERS IN AN AGENT-BASED MODEL OF BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

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KEYWORDS

Agent-based modelling, decision support systems, management of dementia.

ABSTRACT

This project focuses on modelling interactions between a patient with progressive cognitive impairment due to dementia and his/her carers. Interactions are seen primarily as a transfer of abilities from one person to another in order to compensate for cognitive deficits. Cognitive abilities of dementia patients decline over time and can be also associated with a decline in ability to regulate affect and to control their own behaviour which may lead to behavioural and psychological symptoms of dementia (BPSD). The preliminary results show that it is possible to model accurately a transfer of abilities between patient and carers and express it as hours of care. Furthermore, the agent-base model illustrates how cognitive decline in patients may influence the balance between informal and formal care during disease progression.

INTRODUCTION

There is an increasing demand for computer modelling of complex behaviours associated with the provision of health services across a variety of settings. Modelling the flow of patients in the emergency department which operates under the constraints of time and limited resources is one good example (van Oostrum et al. 2008). This demand is driven primarily by an increased understanding that clinical decisions are frequently too complex for human decision-makers to be made quickly and accurately and that utilisation of modern computational techniques may help to overcome these limitations (Brandeau 2005). Computer modelling and simulation has well been recognised in technical disciplines but only recently have these methodologies been adopted by researchers in the social sciences and medicine. Perhaps one reason for this situation has been the lack of software simulation tools which do not require a high level of programming skills. Another reason could be lack of interest and poor understanding of complexities involved in modelling real behaviours of real people. In this paper we will attempt to describe with reasonable detail the main issues and questions faced by health professionals working with dementia patients. We will also describe our effort to model some of the aspects of care for patients with dementia.

Typically the 'dementia story' starts at home and finishes in a permanent residential aged care facility. There is a background of continuous cognitive decline and an increase in the level of care required (Doddy et al. 2010). Initially the role of an informal carer is adopted by a family member but gradually over time this role is assisted by formal carer(s). Therefore during the moderate stage of dementia there is a progressive shift from mostly informal to mostly formal care which often requires a shift from home to a residential care facility (Knopman et al. 1999). Against this background there are intermittent, often daily, challenging patient behaviours to which the carer responds with the assistance of a variety of services and interventions e.g. medication and/or behavioural and environmental interventions. Changes in care needs, care arrangements, services, interventions and stressors are mediated through changes in the patient's abilities to think, feel and act appropriately to the social context.

Psychological and Behavioural Abilities

In order to accurately model the behaviour of patients and their carers it is necessary to provide a simple and coherent conceptual framework within which psychological and behavioural processes can be analysed and understood in the same way for both the patient and the carer. However patients and carers vary in their numerous individual characteristics which affect their ability to think, feel and to control own social behaviours and level of arousal. These abilities can be represented as four latent variables and used to reduce the dimensionality of the model. For example thinking can be represented as PC (psychological cognitive) ability, feeling positive or negative emotions can be represented as PA (psychological affective) ability, controlling behavioural alertness and arousal can be represented as BA (behavioural arousal) ability, and controlling social behaviour can be represented as BS (behavioural social) ability. These four latent variables represent four major abilities of a person who is psychologically and behaviourally 'in tune with the world' and therefore able to self adjust to changes in internal and external environment. Of course there are many factors which influence the way in which these four abilities are increased or decreased. Figure 1 illustrates these four variables and their acronyms.
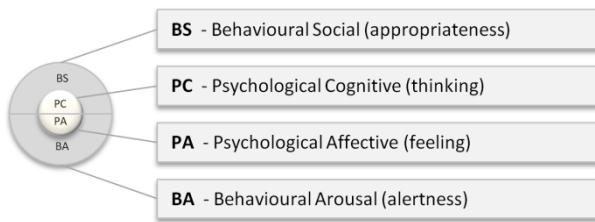
Figure 1. The Latent Variables Describing a Person in an Agent-Based Model of BPSD Management

PC: Psychological cognitive abilities of the patient can be complemented with the abilities of the carer. The carer becomes an extension of the diminished patient's abilities, primarily by 'providing' the ability to remember, to recognise others, to make decision, pay bills, keep appointments and navigate through their physical environment. Psychological cognitive abilities can be interfered with by dementia specific drugs such as Aricept or anti-psychotic medication in order to improve concentration, memory or reduce hallucinations. In more advanced dementia the benefits of pharmacological interventions are small if not negligible (Geldmacher 2004).

PA: Psychological affective abilities can be either increased or decreased by human-human interactions. It is a complex process not well understood in psychology but communication and intimacy with other people seems to be essential for maintaining emotional self-regulation. Emotional states such as loss, grief and sorrow, so frequently present in the life of an elderly person, require immediate and compassionate attention. It will be challenging to make estimates of how many hours of human contact is required to lift the spirit of a moderately depressed person but what is true is that this humane contact is required on a regular basis. Psychological affective abilities can be interfered with by antidepressants and anxiolytic drugs, which are routinely prescribed for elderly patients (Locca et al. 2008).

BS: Socially appropriate behaviour can be directly modified by either learning what is acceptable (very limited in dementia patients) or by guiding how to do things in a socially acceptable way. Cognitive decline in dementia patients can contribute strongly to occurrence of socially inappropriate behaviour due to diminished executive functions and reduced self control (Voss and Bullock 2004). Behavioural social (appropriateness) ability can't be directly modified by medications but such behaviours can be indirectly controlled by *lowering* behavioural alertness (BA). For example the concept of a chemical straight jacket applies here in controlling more severe cases of aggression. Lowering sexual arousal with hormonal treatment may also reduce the incidence of dis-inhibition or aggression against others (Rosin and Raskind 2005).

BA: Behavioural alertness of the patient with dementia can be influenced by the carer who initiates various stimulating activities. Neglect may have an opposite effect. Daily routines, a structured physical environment and maintaining a regular day-night rhythm may have a direct therapeutic influence. Behavioural alertness can be easily modified by pharmacological interventions, primarily by muscle relaxants or sedatives. Unfortunately by lowering behavioural alertness the ability of the patient to control other aspects of life which depend on being awake, upright and focused will deteriorate at the same time (Bell et al. 2010).

Little is known about exact individual trajectories of psychological cognitive (PC) decline in Alzheimer's and other dementias. Recently published studies indicate that the rate of cognitive decline varies substantially between patients and different types of dementia (Xie et al. 2009). However reasonably accurate assumptions can be made regarding the longer term decline of PC, which is in a range of 1-2 points per year on Mini-Mental State Examination scale (MMSE). Individual trajectories of decline in psychological affective (PA) abilities are not well known but there is an assumption that these may strongly depend on reinforcing / inhibiting feedbacks between cognition and affect. The overall impact of decline in PC and PA may be very strong in many patients and eventually manifest as psychological and behavioural symptoms of dementia (Brodaty et al. 2003).

Patient and Carer

In order to keep a relatively simple framework for the model the role of the patient is 'assigned' at the time of dementia diagnosis. The role of the carer is assigned at the same time to another close or related person (e.g. spouse, child, sibling or friend). Initially there is no difference between the two persons who in future will form patient-carer relationship e.g. married couple or siblings. Both have all four PC, PA, BA and BS variables within a healthy range of 7-10 on ten point scale. This is illustrated in Figure 2 as equal and indistinguishable circles with identical size and colour.

Figure 2. A Potential Patient and Carer

The patient-carer relationship is formed when one person's declining abilities are substituted or helped with the abilities of another person. This approach can be easily understood by anyone who at some stage was

either ill (adopted the role of a patient) or was taking care of someone who was ill for a period of time (assumed the role of a carer) (Taylor et al. 2008). In dementia, as in other chronic incurable diseases, the role of the patient is never reversed. Similarly, the need for the role of a carer is persistent. Figure 3 illustrates the patient-carer relationship as connecting lines between two people (virtual objects) which are used in visualising the model.

Formal and Informal Carers

As dementia progresses there may be a variety of carers who provide help to the patient. In the majority of cases the first carer is an unpaid family member or friend, known as an informal carer (Australian Institute of Health and Welfare 2006). As the severity of dementia symptoms increases and level of patient's abilities declines, paid formal carers are gradually introduced to this patient-carer relationship. Figure 3 illustrates three such cases in (A) the family home, (B) community care, and (C) a nursing home, showing the respective interactions between patients (red circles) and informal (light green circles) and formal carers (dark green circles).
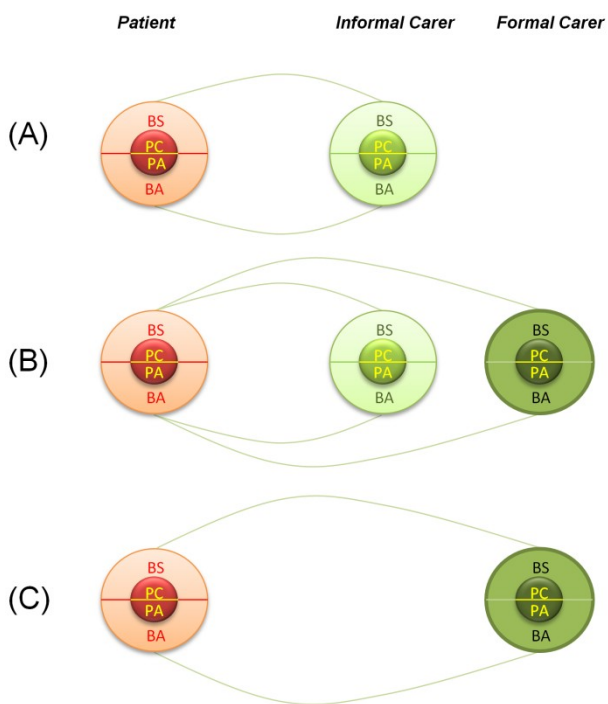

Figure 3. Three Scenarios Illustrating Patient-Carer Interactions in Different Settings

Relocation of the patient with dementia to a nursing home is the commonest transition from mainly informal to mainly formal care. The involvement of informal and formal carers is regulated primarily by the willingness of the informal carer to become a carer in the first place and then to continue the carer role (Access Economics 2005). After all, it is a voluntary role governed by social custom, family ties, emotional attachments and personal goals (Bridges-Webb et al. 2007).

In the agent-based model the concept of transfer of abilities is very important because it helps to illustrate changes in both patients and carers over time. The general assumption here is that longer the person is a carer the more depleted are her/his abilities. Carers frequently report to be 'mentally exhausted' and 'emotionally drained' as a result of long term care for patient with dementia (Etters 2008). These may lead to conditions called 'burnout' which results in a decision of total withdrawal from the role of informal carer.

Transfer of Abilities

In essence this transfer of abilities is based on a demand-supply interaction. A sufficient and appropriate amount of care should lead to slower decline and better overall quality of life. The unmet needs of the patient will eventually cause further and faster decline of remaining abilities. Therefore in this context a continuous draining of the carer's abilities may eventually result in burnout and withdrawal from the role of the carer. Both situations should be avoided in good quality care, which includes opportunities for carers to renew or recharge their abilities. The care provided by informal carer such as spouse or child is strongly dependent on the willingness of that person to play such a role (Norton et al. 2009).

The amounts of abilities which are 'transferred' from carer to patient also depend on other factors. These transfer factors include the number of carers engaged in care during a time period, the hours of care provided by each carer on a sustainable basis and the level of skills and motivation of the carer to provide optimal care. Figure 4 illustrates our assumptions regarding the trajectory of decline of the patient's overall abilities and the carer's effort to compensate for this decline over time. This assumption will be tested in the computer model.
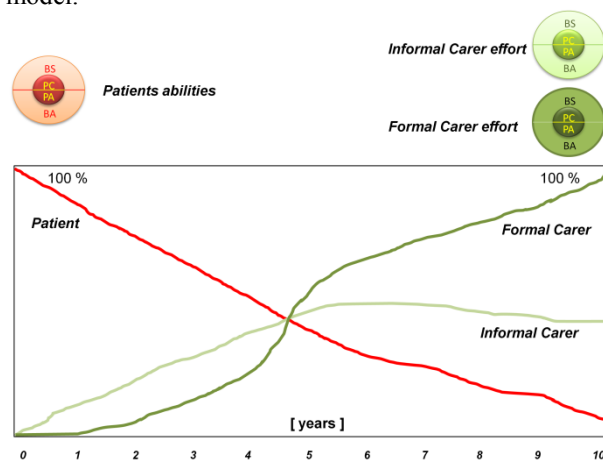

Figure 4. Assumptions of Decline in Patient's Abilities vs. Effort from Informal and Formal Carers

The informal carer effort is initially very high and is the only source of care in mild dementia (Access Economics 2005). With an increase in symptom severity the willingness of the informal carer to provide care may change drastically. Studies show that in moderate dementia informal carers seek help from respite services (Lee and Cameron 2004). After a period of time decisions are made to transfer patients form family home to residential care facilities such as nursing homes or community assisted living in hostels or group homes. Only about 15 % of patients with severe dementia are being cared for at home (Australian Institute of Health and Welfare 2006).

In an effort to better understand the management of dementia and in particular management of behavioural and psychological symptoms of dementia we created an agent based model which focuses on patient-carer relationships.

AIMS

The aim of this project was to test the following assumptions: (a) dynamic changes in the relation between patient and carer can be expressed as hours of care provided by formal and informal carers (b) willingness to become a carer can be used as a driver to model transition from mainly informal to mainly formal care.

METHODOLOGY

The AnyLogic simulation software was used as a programming tool to build the model (XJ Technologies 2011). An agent representing the patient, informal carer and formal carer was initialised at the beginning of simulation for each of the dementia patients. Each of the agents carried the same initial characteristics. The time step of the model was one week with the run length of maximum 500 steps which is the equivalent of 10 years in a patient's life.

The number of hours for the total care needed was represented as a function of patient's decreasing cognitive abilities $PC_{patient}$ and affective abilities $PA_{patient}$. In the first instance these values were derived from the lookup table which included average assumption from the published literature (Australian Institute of Health and Welfare 2006; Access Economics 2005). The maximum care hours were set up as 35 per week and calculated as:

$$Total\_Care\_Needed_{dt} = f_{dt}(PC_{patient}) + f_{dt}(PA_{patient}) \quad (1)$$

Two out of four latent variables (PC and PA) contributed to the formula which was used as a primary driver in the transition between informal and formal care:

$$Willingness\_To\_Be\_Carer_{dt} = f_{dt}(PC_{carer}) + f_{dt}(PA_{carer}) \quad (2)$$

The number of hours of informal care was estimated by the following formula:

$$Informal\_Care_{dt} = Total\_Care\_Needed_{dt} * Willingness\_To\_Be\_Carer_{dt} \quad (3)$$

The number of hours for formal care was calculated as the remaining hours needed when informal care was completed:

$$Formal\_Care_{dt} = Total\_Care\_Needed_{dt} - Informal\_Care_{dt} \quad (4)$$

Latent variables BS and BA were excluded from the above formulas at this stage but will be included in the next version of the model. Considering the interdependence among the four latent variables in this model it can be appreciated that inclusion of BS and BA variables required further research effort.

RESULTS

Only preliminary results of the experiment are presented in this paper. Figure 5 shows a progressive decline in cognitive abilities of the patient with dementia over time as a red line. Initially psychological PC ability is at the high level and after period of 10 years (500 weeks) it gradually drops to a level below 10 % which corresponds to severe dementia. The decline in psychological affective ability PA is assumed to be negligible in this experiment. These values are arbitrary and representative of an average patient only. The total hours of care needed for the patient is closely linked to decline in $PC_{patient}$ and $PA_{patient}$ as indicated by the black line. Values are expressed as a percentage of maximum 35 hours of care per week (Access Economics 2005). The willingness to be a carer (blue line) gradually drops from initial 100 % to less than 10 % and reflects decline in PC_{carer} and PA_{carer} of the informal carer.
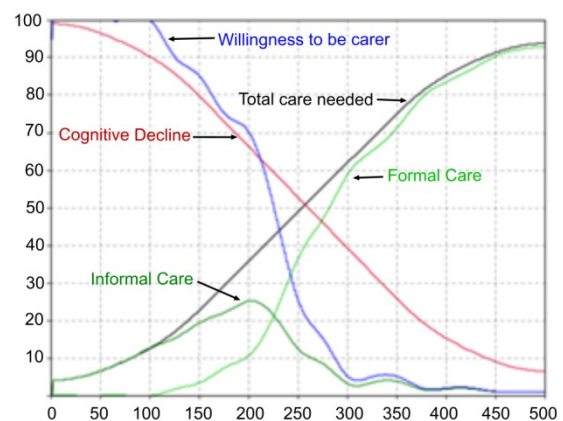

Figure 5. Assumptions and Outcomes of Patient-Carer Relationship as Represented by Hours of Care

Initially the number of hours of informal care (dark green line) steadily increases in parallel with an increase of total care needed until a willingness to be a carer declines. This generally happens after 4-5 years of care (200-250 weeks). From that point on, which

corresponds to moderate dementia, the number of informal hours drop and the patient's care starts to be provided by two carers. In severe dementia (300-500 weeks) care is provided primarily by formal carer(s) as illustrated by light green line.

DISCUSSION

Previous attempts to model BPSD patients and services have used several key constructs, including the ability to respond to stressors, changes in various care needs and various care arrangements, a range of services and interventions used during progression of disease and types of medical services available in each setting for specific BPSD symptoms such as depression or aggression (Brodaty 2003). This approach was far too complex for model development and required multiple agents to represent multiple objects and functions. Here we aim to use a framework which represents a much simpler and more manageable approach to modelling complex interactions in dementia management. In our current approach the essential characteristics of an individual patient with behavioural and psychological symptoms of dementia are summarised, apart from usual demographic characteristics such as gender, age and location, by just four latent variables in a way similar to that published by Proitsi et. al. (2009). Such approach has also good theoretical support in recent proposal by National Institute of Health (USA) to shift classification of disease from symptomatic (e.g. DSM IV classification) to systemic classification based on physiological and neurological findings (Miller 2010). In our modelling approach patient and carers have identical characteristics expressed by four variables PC, PA, BS and BA. Specific values of these variables determine the role which the agent plays in the model and, in case of the informal and formal carers, the amount of care provided.

The hours of total care which are needed have been calculated based on cognitive abilities and affective abilities of the patient with progressive dementia. The hours of care provided by informal carer were calculated based on his/her willingness to continue in a role of a carer. Therefore hours of care, needed and provided, are becoming a central axis through which relationship between patient and carer is expressed in the model. Numerous factors which influence the patient's need can then be translated into one common denominator. The same common denominator of 'hours' could apply to factors influencing care giving. For example all complex factors which influence the informal carer's decision to continue, reduce or withdraw from that role are summed up as 'willingness to be a carer' and used as attenuator of hours of care provided.

A similar approach will apply to modeling the effects of various therapeutic interventions. Initially we assumed that effective intervention could only be provided in three ways: (a) pharmacological interventions which influence PC and PA through modification of neurochemistry of the brain, (b) removal of major stressors through pain management and/or changes in the environment, and (c) effective and timely care provided by informal and formal carers which maintains physical and mental wellbeing of the patient. All three scenarios can now be modelled separately and in combination.

In the next version of the model we plan to introduce further refinements without increasing the basic complexity. Such an approach will combine the current methods of modelling BPSD, which are commonly overly-complex, with a method that remains conceptually and technically simple. To do so it will be integral to understand the intricate nature of how patient and carer characteristics change over time. For example it is common knowledge that carer skills can be increased by improved training appropriate to informal and formal care. Modelling this behaviour would need to take into account the individual carers who seek assistance in providing care to the patient but also in how they might set expectations and influence the perceptions of other carers.

We expect that the use of the agent based computer model and virtual experiments will help policy makers to reduce uncertainties and improve understanding how policy decisions made today will impact on patient-carer networks over time. Because the conceptual framework is the same for people with dementia and people with a role of a carer, it is easy to see how modification of each role is possible without reaching for different sets of cognitive constructs. Each virtual patient with dementia has a simple structure representing capacity to think (PC) and to feel (PA) with additional characteristics of ability to control arousal and alertness (BA) and control of social appropriateness (BS). We believe that this new framework allows us to model real life scenarios and pathways of care for patients with dementia and to improve clarity of thinking about the management of BPSD.

ACKNOWLEDGEMENTS

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