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Using social network analysis to model palliative care

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ABSTRACT

Palliative and end-of-life care are special types of healthcare that focus on improving the quality of life of patients who are living with life-threatening illness or nearing their end of life. The primary goal here is to provide various support services to help the patients to maintain an active life and dignity. Assuming there are cost and resource limitations for delivering care within the system, where each care provider can support a limited number of patients, the problem can be defined as finding a set of suitable care providers with a minimum overall cost to match the needs of the maximum number of patients.

In the grand scheme, the whole care system can be seen as a social network consisting of patients and care providers. This representation provides an opportunity to apply social network analysis techniques to enhance the topology of the system and improve its efficiency. In this paper, we propose a novel computational agent-based model to address this problem by extending the agent's capabilities using the benefits of the social network. We assume that each patient agent can cover its disabilities and perform its desired tasks through collaboration with other agents. The primary objective is to optimize a dynamic, personalized care pathway system that will support palliative care within a community eco-system. Testing the ability of the system to match social support agents with personal preferences, needs, and capabilities is the second goal of this research work. In addition, we are going to measure the impact of the system on perceived quality of life, social connectedness, caregiver burden, and care satisfaction. The performance and functionality of our proposed model have been evaluated using various synthetic and a real palliative networks. The results demonstrate a significant reduction in the operational costs and enhancement of the service quality.

1. Introduction

The aging population has been growing rapidly in the world Melorose et al. (2015). Progressive loss of function and co-morbidities associated with aging exacerbate social isolation, depression, and fragmented care. This negatively affects quality of life for the patients and their caregivers and increases sub-optimal use of health care services. Therefore, shifting to the triple value healthcare paradigm (Personal, Technical and Allocative) can be considered as an approach to improve the quality and delivery of the services Jani et al. (2018); Gray et al. (2017); Silenzi and Boccia (2017). The first objective is to optimize personal values by ensuring that decision making is performed based on the individual patient's values. The next objectives are to allocate and utilize the resources optimally and equitably. In addition, some recent research shows that enabling patients to direct their own care path and enhancing their social supports have positive impacts on improving their health and overall well-being. Goswami et al. (2010); Cotten et al. (2013); Chen and Schulz (2016); Jani et al. (2018); Gray et al. (2017); Silenzi and Boccia (2017).

A pragmatic solution to support health aging lies in activating resources that exist within a community eco-system. Social networks within a community system are interconnected, interactive, and dynamic. Knowledge about these networks can be used to reduce the person's unmet needs and guide interventions that enhance person-centred care. Leveraging community social capital as an often untapped, yet readily available and renewable resource magnifies impact and population scalability. Social network analysis is a powerful tool that can assess and purposefully facilitate social connections.

In a high level view, health care systems can be seen as social networks consisting of patients, care providers, organizations, volunteers, and other attributes that are linked together through shared entities. Unfortunately, these linkages are often poorly understood, and therefore not well-connected. In this paper, we propose an agent-based approach to apply social network analysis techniques to model palliative

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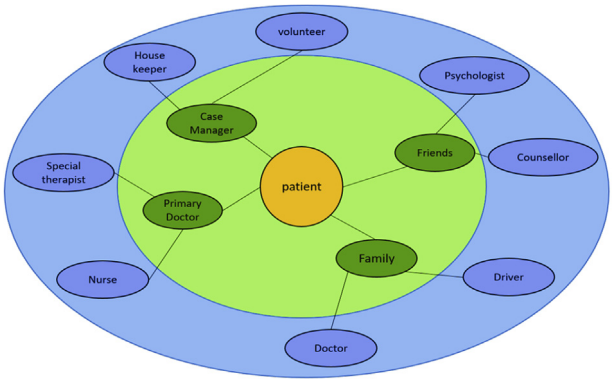

Fig. 1. Social care circle in a palliative care system.

care networks and design a decision-support system that predicts best fit care 'agents' based on the patients' self-identified needs, goals, and capabilities to improve goal achievement, social connectedness, quality of life, satisfaction with care and reduce caregiver burden.

In palliative and end of life care, enhancing the quality of life of patients who are living with life-threatening illness or nearing the end of life is the key objective. This type of care may be taken into account if there is no chance for a cure or recovery, therefore, the goal is to provide various support services to help the patients to maintain an active life and dignity Tsavatewa et al. (2012). As demonstrated in Fig. 1, a team of formal and informal care providers including family members, nurses, volunteers, and doctors are involved in this process.

As Fig. 2 shows, the process starts by determining the overall health status and well-being of a patient which is usually carried out through conducting interview meetings and questionnaires Higginson et al. (1990). After that, a personal care plan will be designed for each patient by the team of care based on the collected information. The plan usually consists of a list of suggested activities and the name, responsibility and role of each care provider.

As a result, each patient has its own social circle of care. Consequently, by merging the social care circles of all the patients, we can make a social network graph of patients and care providers. This representation provides an opportunity to apply social network analysis techniques to enhance the topology of the system and increase its efficiency. Considering the profile informations, this approach can improve the quality of services for the patients with similar problems, disorders, and needs. It can also enhance the human resource allocation's process and reduce operational costs by optimizing the network and assigning most appropriate care providers to the patients. Finding the patterns, extracting features and predicting the evolution of the care system are other advantages of this approach.

For example, in the community addressed in this study, there is a variety of services that are offered on a volunteer basis, such as socialization programs and transportation. These services are required by many people in the target population (e.g. over 80 years old, palliative, with chronic disease or disability). Although these services can clearly benefit the population in a cost-effective manner, the demand is too large for the supply and there are often long wait lists for these services. By using this algorithm to visualize communities in terms of people who are in need and those who are willing to provide the service, we can physically see where the demand is. This has the potential to allow for a better allocation of resources.

As palliative care is a complex dynamic social system, to start the analysis, we have to first describe its domain and components in an appropriate computable form. In this research paper, we use an agent-based approach to model the system. Our next objective is to propose a care planning algorithm to help the care providers and patients in the decision-making process. The output of this research work will be an agent-based framework which can be used as a decision support system to recommend a team of formal and informal care providers to patients based on the required capabilities, available resources and minimum overall costs. The performance and functionality of this model are evaluated based on various networks and scenarios. To the best of our knowledge, it is the first attempt in the field to make a practical computational model to represent the palliative and end-of-life care systems.

The rest of the paper is organized as follows. The problem statement is defined in the next section. Related works are briefly reviewed in Section 3. Our proposed model and algorithm are described in Section 4. The evaluation methods and the results are discussed in Section 5 and 6. Finally, conclusion is the last section.

2. Problem statement

As mentioned before, patients and care providers are the key social actors in the palliative care system. Each patient has a set of capabilities and goals, which can be defined as $ag^p \in AG \triangleq (G_{ag^p}, C_{ag^p})$, where $C_{ag^p} = \{c_1, ..., c_n\}$ denotes the set of n capabilities for each patient. For example, c_1 can be the ability of walking independently, and c_2 the capability of driving. For each patient, the set of capabilities can be split into two sets of internal and external capabilities, hence $C_{ag^p} = \{C_{IN} \cup C_{EX}\}$ and $C_{EX} \cap C_{IN} = \emptyset$. The internal capabilities are those abilities that a patient already have which is represented by a fixed-size binary vector as $C_{IN} = [c_1, \ldots, c_n]$, where c_i, $1 \le i \le n$, is 1 if a patient has the corresponding ability and it is 0 in the other case.

The external capabilities are those abilities that a patient does not have but can be obtained with the help of the care providers. It is represented by a fixed-size binary vector as $C_{EX} = [c_1, \ldots, c_n]$.

In addition, each patient has a set of goals which can be achieved by performing some specific tasks. Let $g \in G_{ag^p} \triangleq (gid, TS)$ shows a goal where gid is used to identify the goal and TS is a set of required tasks to achieve it. Each task is defined as $ts \in TS \triangleq (tid, RC)$ where, RC is the required capabilities to perform the task and is represented as $RC \triangleq (rc_1, \ldots, rc_m)$.

The main problem here is that the patients can not achieve some of their desired goals because of the fact that they do not have enough internal capabilities to perform the required tasks of these goals, $\{\exists RC | RC \not\subseteq C_{IN}\}$. For example in Fig. 3, the patient wants to achieve "Goal 1" which requires performing Tasks 1, 2 and 3. Hence, three capabilities of c_1, c_2 and c_3 are required to perform the task 1. Meanwhile, the required capabilities for task 2 are c_1, c_4 and c_5, and for the task 3 the capability of c_2 is required. As the patient does not have c_4 in the internal capabilities, it can not perform the second required task and consequently can not reach the goal.

One method to cover this weakness, is to use the external capabilities. In fact, by the help of care providers patients can get extra supports to perform their desired tasks. However, each care provider can support only limited number of patients and also it usually can not supply all of the required capabilities. Hence, a team of care providers usually is needed to support a patient. Assuming there is a

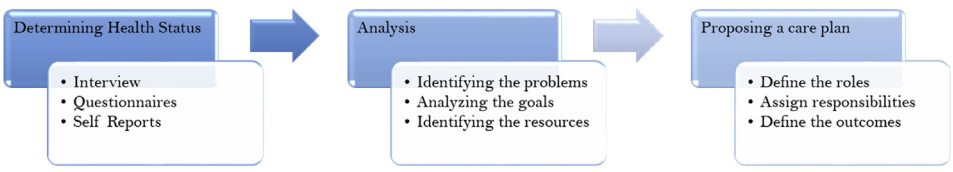

Fig. 2. A process of producing a personal care plan.