Using a Modelling Language to Describe the Quality of Life Goals of People Living with Dementia

Experience Paper

James Lockerbie and Neil Maiden

Centre for Creativity in Professional Practice, Cass Business School, 106 Bunhill Row, London EC1Y 8TZ, United Kingdom

James.Lockerbie.1@city.ac.uk

Abstract. Although now well established, our information systems engineering theories and methods are applied only rarely in disciplines beyond systems development. This paper reports the application of the *i** goal modelling language to describe the types of and relationships between quality of life goals of people living with dementia. Published social care frameworks to manage and improve the lives of people with dementia were reviewed to synthesize, for the first time, a comprehensive conceptual model of the types of goals of people living with dementia. Although the quality of life goal model was developed in order to construct automated reasoning capabilities in a new digital toolset that people with dementia can use for life planning, the multi-stage modelling exercise provided valuable insights into quality of life and dementia care practices of both researchers and experienced practitioners in the field.

Keywords: Dementia, quality of life, interactive toolset, goal modeling

1 Introduction

Information systems engineering theories and methods are well established in their disciplines. Outcomes from basic and applied research results that are reported in conferences such as CAiSE have transformed into maturing information systems engineering practices. Examples of these practices include business modelling formalisms [1], product variability and configuration management mechanisms [4], and goal modelling techniques [31]. In turn, these maturing practices have created new research opportunities in information systems engineering and other disciplines.

Unsurprisingly, however, most reported information systems engineering practices have been undertaken by people working to model and analyze more traditional types of information systems in domains such as person-centric healthcare [5] and air traffic management systems [15]. By contrast, there has been relatively little cross-discipline use made of the research and practices in domains as diverse as creative leadership, sports training and the care of older people. Alas, this current limited use represents missed opportunities.

One missed opportunity, which is the focus of this paper, is to support the care for people living with chronic diseases such as dementia. Dementia has emerged over the last decade as a major societal challenge due to the increased ageing of populations, especially in more advanced economies. As well as becoming a new social care challenge and a source of individual human distress, it has major economic impacts – the economic cost of dementia worldwide has been estimated to be US$818 billion annually, rising to US$2 trillion by 2029 [20].

In this paper we report the use of an advanced goal modelling method from information systems engineering to understand, model and synthesise existing social care frameworks of quality of life of people living with dementia. The paper presents a new goal model of quality of life to be used for the development and implementation of automated reasoning capabilities to be embedded in *EnableSelfCare*, a new toolset for quality of life planning by people living with dementia.

The rest of this paper is in 5 sections. Section 2 summarises dementia and its impacts, and reports on examples of social care and digital research and practices that have been developed to improve the lives of people living with dementia. Sections 3 and 4 outline the new *EnableSelfCare* toolset under development and the rationale for using the *i** goal modelling language to model quality of life as part of the toolset. Section 5 reports the development of the new quality of life goal model, and demonstrates the model's characteristics with indicative examples. The paper ends with an exposé of insights gained from the application of the goal modelling language to a social care problem, and draws first conclusions for uses in other non-engineering domains.

2 Dementia Care Practices and Technologies

Dementia is a decline in mental ability that affects memory, thinking, concentration and perception. It occurs because of the death of brain cells or damage in parts of the brain that deal with thought processes. The number of people with it worldwide has been estimated at 47.8 million, a figure expected to double in 20 years. Alzheimer's disease is a common cause of dementia that accounts for up to 70% of all cases.

The presence of dementia impacts substantially on the person's defined quality of life, often from before diagnosis to end of life. A defined quality of life [22] derives from the World Health Organization's definition of *health*, and concerns not only the absence of disease or infirmity but also the presence of physical, mental and social wellbeing [30]. Quality of life has increasingly been used as an outcome of medical research. However, whilst there is a considerable literature relating to it (e.g. [28]), a single and accepted model of quality of life is still missing [25]. Furthermore, many people with dementia also have co-morbidities – other illnesses such as Parkinson's disease, diabetes and anaemia – that add to barriers to a defined quality of life.

Over the last 20 years, different activities of daily life with the potential to overcome barriers and maintain aspects of quality of life have been reported widely. Better-known examples of these activities include the person listening to their favourite music and reminiscing about past experiences [29]. In response, professional services

such as the UK's Alzheimer's Society have started to provide online information about the more common types of these activities. However, most of these common activities improve some but not all aspects of the quality of the lives of people with dementia. Moreover, the associations between the common types of meaningful activities and the quality of life benefits that are claimed for them are still poorly understood, and there is no single source that defines these associations.

2.1 Digital Technologies to Support People Living with Dementia

Most of the computer science research related to dementia has focused on technologies to support the early and effective diagnosis of the condition using, for example brain images [26] and magnetic resonance spectroscopy data [17]. To design such technologies, researchers such as [23] have reported the elicitation of new causal models of dementia diagnosis with domain experts.

More relevant to our work, some interactive digital technologies have been demonstrated to support people living with dementia to improve aspects of their quality of life after diagnosis. For example, Cowans et al. [7] reported early work that utilized interactive multimedia to stimulate long-term memory to prompt communication as part of reminiscence therapy for people with dementia. Cahill et al. [3] argued that assistive technologies can make a significant difference to the lives of people with dementia and to their care workers if delivered at home in a thoughtful and sensitive and ethical way. Wallace et al. [27] described the use of computing devices designed as furniture pieces by older residents to provide notions of home, intimacy and possessions with which to develop a sense of personhood. Thiry et al. [24] reported work in which older people made personal digital timelines using technologies designed to support the building of memory. Lazar et al. [14] reported the design and exploration of *Moments*, a prototype system that allowed individuals living with dementia to share their artwork with others in the network by manipulating their physical environment. And immersive interactions with virtual environments of familiar places and activities have been shown to improve some aspects of the physical and emotional wellbeing of people with dementia [10].

As these examples demonstrate, most of the research to develop new technologies to support people living with dementia relies on action research focusing on early digital prototypes in use by people living with dementia. One consequence is that few of the reported research prototypes have been evolved into production-level systems. By contrast, no applications of information systems engineering to the problems of people living with dementia have been reported, and little digital support for wider quality of life planning and improvement is available.

More generally, the types of artificial intelligence technique that have been applied successfully to support healthcare include case-based reasoning to plan radiotherapy treatments, Bayesian Belief Networks to diagnose liver disorders and artificial neural networks to predict Parkinson's tremor onset. Although effective, most were developed to manage individual medical conditions, rather than support people living with complex degenerative conditions and co-morbidities such as dementia. Now, the emerging need to support people to achieve quality of life with complex degenerative

conditions such as dementia creates new opportunities for artificial intelligence in social care and healthcare – opportunities that, on the whole, have yet to be taken.

2.2 Social Care Approaches to Supporting People Living with Dementia

Social care research has led to different quality of life frameworks to help people with dementia understand and communicate their life preferences and needs. Most of these still focus on selected aspects of the person's preferences and needs, such as framing a person's quality of life choices [13], describing personal outcomes [2] or documenting preferred meaningful activities [18]. None support all of a person's quality of life preferences and needs.

Furthermore, these frameworks were developed for carers to use manually, so there are no reported attempts to make the guidance from these frameworks automatic and accessible to carers with all but the most simple of digital tools. Indeed, guidance is normally reported using informal language. For example, practical guidance for care professionals for describing personal outcomes [19] is presented as narrative and tables such as in Table 1. The guidance is informal, the presented concepts are not defined, and no structure between these concepts is reported (e.g. between *health* and *mobility*, or between *being listened to* and *being respected*), which results in ambiguities, inconsistencies and overlaps between concepts (e.g. between *I see people* and *I belong to a community*).

Table 1: Lists of outcomes important to people living in care homes, as described in a practical guide for personal outcomes in [19]

Quality of Life	Process	Change
• I feel safe and secure • I see people • I have things to do • I live in a nice place • I live life as I want and where I want	• I am treated as an individual • I am valued and respected • I am listened to • I have a say in decisions about my care and support • I am supported to live well and plan for a good end of life	• My skills are improved • My confidence and morale are improved • My mobility is improved • My health has improved or my symptoms are reduced

Although an experienced carer can interpret the ambiguities and inconsistencies in the guidance for the needs of each individual, the informality impedes the development of all but the most basic digital support based on these frameworks.

Furthermore such frameworks, in their current forms, are not usable to support the use of emerging technologies that increase automation in dementia care using, for example, the Internet of Things, big data analytics and machine learning. Indeed, these frameworks were designed to be used with volumes of data that are orders of magnitude smaller than can be collected using digital sensors, and process this data less frequently than is possible with real-time data collection.

To conclude, our review of social care frameworks revealed an opportunity to apply information systems engineering theories and methods to model and synthesise concepts related to the quality of life of people with dementia. One planned outcome

of this modelling work would be to inform the development of a new digital toolset for use by people with dementia to plan to improve the qualities of their lives. The next section introduces one such toolset, and the pivotal role of a new quality of life goal model in that toolset.

3 The *EnableSelfCare* Toolset

The use of documented plans for the lives of people with dementia – plans that describe the life requirements and the meaningful activities to undertake to contribute to these requirements to maintain and acquire – is becoming commonplace. Increasingly, these plans are documented using digital tools. However, although domestic sensors are also now available and used to monitor people with dementia [12], these sensors are not integrated meaningfully with their digital plans that describe the requirements and associated activities to be monitored. This gap can result in interventions that might be inconsistent with the person's requirements.

Therefore, the future *EnableSelfCare* toolset will allow a person with dementia living in their own home to plan, monitor and self-manage his or her life and wellbeing. The person will interact with the toolset using a simple interface to describe and change requirements and meaningful activities that s/he desires to maintain, achieve and undertake. These requirements will be used to configure a simple set of low-cost sensors to collect data about, for example, movement and applied pressure associated with the activities. Data fusion algorithms will generate descriptions of the person's activities from data collected from these sensors – descriptions that will provide the input data to a computational version of a new quality of life goal model. The model will use these descriptions to infer whether desired requirements associated with these activities are achieved. The toolset architecture is depicted in Figure 1. Its intelligence will derive from the completeness and accuracy of the model.

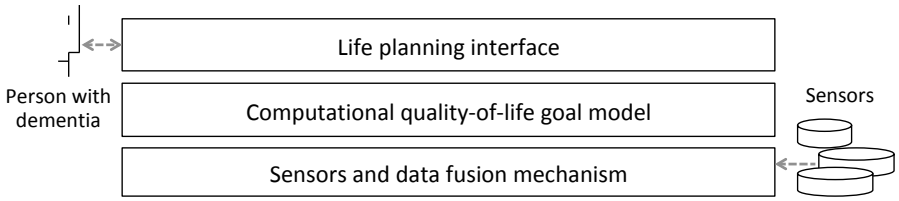

Fig 1. Simplified architecture of the *EnableSelfCare* toolset

Therefore, development of this goal model became a major research task.

4 Using the *i** Goal Modelling Language

To enable precise representation of and analyses about the goal types derived from the existing social care frameworks, the model was developed using the *i** goal modeling language [31] from information systems engineering. The *i** language enables the modeling of intentions of different actors in a social system, and has been applied

to analyze goals and associations in complex systems in, for example, healthcare monitoring systems [16]. With *i**, an actor seeks to achieve or attain an end element, which in *i** can be a soft goal or a goal. An actor also has the means to achieve or attain the end element. In *i** a means can be a goal, soft goal, a task, or a resource. The actor seeks to attain a goal (a desirable state) and undertake a task (so that a goal might be attained). With soft goal contributes-to links, the achievement of one soft goal can contribute positively or negatively to achieving another soft goal. Where the end element of the links is a soft goal, the relationship can be attributed with values that specify the modality and type of the contribution (*Some+, Some-, Help, Hurt, Make, Break, Unknown*), as reported in [31].

Some of the *i** model semantics mapped well to content that was extracted from the different quality of life framework elements, indicating that it could be an effective language with which to describe the intentions of people living with dementia. *i** soft goals were effective for describing types of state that the person desired to achieve, such as qualities of life and personal outcomes. Examples of these soft goal types included *social life maintained* and *cognitive function maintained. i** tasks were effective for describing the meaningful activity types that the person sought to undertake, for example *to stroll in garden* and *to make own lunch*. And *i** contributes-to links could be applied to describe how the completion of types of meaningful activity contributed to achieving different types of soft goals, and how soft goal type achievement contributed to the achievement of other soft goal types.

5 Developing the New Quality of Life Goal Model

To develop a first version of the new quality of life model, we conducted a review of academic literature on quality of life. At stages, to direct the review, we consulted about the review findings with leading academics and practitioners in dementia care. Based on these consultations we sometimes reviewed other literatures. And during these reviews, we developed informal versions of the model by extracting goal types from the frameworks and documented these types using semi-structured graphical notations. When it was assessed to be sufficiently complete, the informal model was described formally using the *i** goal modeling language.

The model was developed to be a general model that would describe the types of goal that would hold for most people living with dementia. As a consequence it described types of goal such as *engaged with neighborhood* rather than instance-level goals such as *engaged with my village's neighborhood watch*. The rest of this section reports each of the model development stages.

The literature review revealed a wide-range of treatments of quality of life in disciplines such as health and nutrition, so we restricted the literature review to quality of life of people living with dementia. Lawton [13] reported that whilst quality of life emerged as a concept at the forefront of gerontology research, much of this research neglected the quality of lives of people with Alzheimer's disease. His subsequent research of quality of life for people living with dementia provided a baseline for many care practice approaches, and was subsequently referenced by other quality of

life dementia frameworks such as the *Bath Assessment of Subjective Quality of Life in Dementia (BASQID)* and *dementia quality of life instrument (DQoL)*. Moreover, Lawton's model is cited as the most pervasive influence on conceptualizing quality of life in dementia [21]. Therefore, the first version of the model and the types of goal that it described was based on Lawton's framework [13].

Although Lawton's framework identified important elements with which to structure the model, it did not define personal goal types of importance to people living with dementia. Person-centred care is now a dominant form of caring for older people with dementia. It is a form of care that seeks an individualized approach that recognizes the uniqueness of the world from the perspective of the person with dementia [4]. After consultations with care academics and practitioners, we conducted a review of the personal outcomes literature (e.g. [2]) associated with person-centred care practices. Personal outcome goals are, by definition, specific to individuals [6], so the review revealed numerous examples of personal goals rather than a comprehensive list of goal types. Therefore, the extracted examples of personal goals were clustered to enable us to generate a smaller set of goal types that represented most of the collected personal goal examples uncovered in the literature. Then, to associate the personal goal types with types of meaningful activities that people can undertake to improve quality of life, we reviewed taxonomies of activities for people with dementia [8]. These taxonomies were used to generate types of goals that a person achieves by completing a single or few instances of types of meaningful activities. The resulting goal types were then associated with a larger set of meaningful activity types that people living with dementia in their own homes might undertake in order to improve the qualities of their lives in different ways.

The basic structure of the goal model is depicted in Fig 2. This model describes a small number of types of soft goal associated with qualities of life that all people living with dementia would seek to achieve. These types of soft goal were then associated with a larger number of types of soft goal that were extracted from goal examples from the personal outcome frameworks. New associations between these soft goal types were then discovered and added to the model. The types of soft goals extracted from the meaningful activities were also then added, and associated via further modelling with both the personal outcomes soft goal types and the larger number of meaningful activity types associated with achieving quality of life.

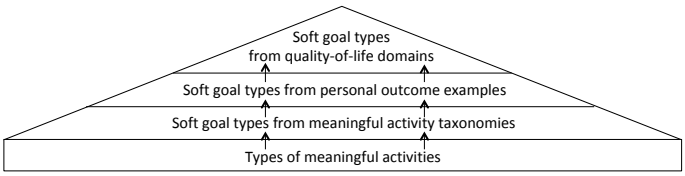

Fig 2. The basic structure of the quality of life goal model derived from social care frameworks

At different points in the process, experienced professional domiciliary carers validated the emerging versions of the quality of life goal model. A total of 7 workshops took place to validate the completeness and the accuracy of the goal types and con-

tributes-to links. The input model to each workshop was updated with changes after the first 3 workshops. To encourage hands-on changes by the carers, the model's digital representation was transformed into a physical one of cards, pins and string, as depicted in Fig 3. Most model transformations were additions of new content such as new types of meaningful activity and changes to contributes-to links between soft goal types. Outcomes from these workshops led to many implemented model changes.

Fig 3. Examples of physical versions of the quality of life goal model used in the workshops

Each part of the new quality of life goal model is described in turn.

5.1 The modeled overall quality of life goal types

Lawton's definition of quality of life with Alzheimer's disease [13] specified 6 quality of life domains: the *ability to perform activities of daily living*, *engaging in the meaningful use of time*, *competent cognitive functioning*, *physical health*, *socially appropriate behavior*, and a *favorable balance between positive and negative emotion* [13]. As Lawton's framework has had a far-reaching influence on conceptualizations of quality of life of people with dementia, 5 of these 6 domains were used to define 5 soft goal types that each person would seek to achieve. The 6th quality of life domain identified by Lawton – *engaged in the meaningful use of time* – was not converted into a soft goal type because it was the premise of all the meaningful activities, and therefore represented by all of the modelled meaningful activity soft goal types. The remaining 5 quality of life soft goal types that structure the quality of life goal model are summarized graphically in Fig 4.

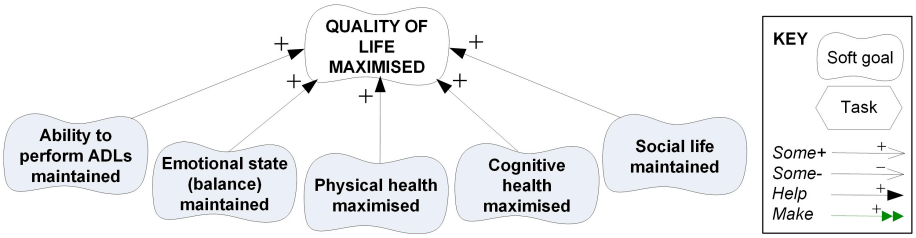

Fig 4. The soft goal types used to structure the quality of life goal model, and key of used i* graphical modelling elements

5.2 The modeled personal outcomes goal types

The different types of soft goal generated from examples of personal outcomes in the frameworks (e.g. [2, 6]) were described in the new quality of life goal model. After analyses of multiple personal goal examples and validation exercises with the professional carers, a total of 40 personal outcome soft goal types were added to the model. Fig 5 depicts 9 of these 40 soft goal types and contributes-to links to 2 of the 5 types of soft goal derived from Lawton's framework [13]. Most of the associations between these 40 soft goal types and the 5 different soft goal types from Lawton's framework were inferred from examples reported in the personal outcomes frameworks. For example, the model describes that the increased achievement of *communication skills maintained*, *learning maintained*, *active mind brain function maintained*, *perceived state of memory maximized* and *ability to concentrate maximized* each contributes positively to achieving the soft goal *cognitive health maximized*.

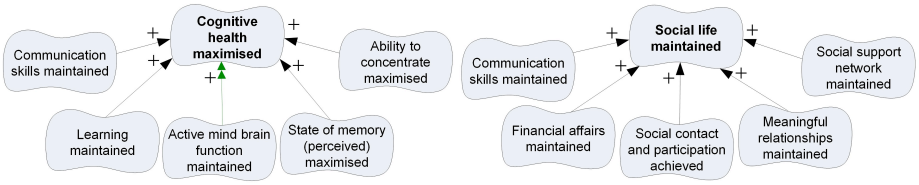

Fig 5. Different types of soft goal generated from the personal outcomes literature associated to quality of life soft goal types

Unsurprisingly, the review revealed a lack of explicit associations between quality of life goals reported in the different sources, so the validation workshops were used to discover and validate missing contribute-to links between soft goal types.

5.3 The modeled goal types associated with meaningful activities

Meaningful activities include physical, social and leisure activities such as *gardening*, *reading* and *singing*. There are many factors that make activities meaningful to an individual that can relate to that person's values, beliefs, past roles, interests and routines [9]. Han et al. [8] synthesized qualitative studies of meaningful activities of people with dementia (e.g. [9]), categorized these meaningful activities and identified themes related to *connectedness* with which to categorize them. The 3 themes described how a person with dementia might seek to connect: (1) to oneself (for example *through maintenance of personal routines*, *engaging in activities to benefit health* and *having personal time and rest*); (2) to others (for example *having social contact*, *doing activities with others* and *maintaining meaningful relationships*) and: (3) to one's environment (for example *being settled at home*, *being involved in the community* and *getting out into nature*). Enabling these different senses of purpose through meaningful activities had been shown to improve the quality of life of people living with dementia (e.g. [18]).

Therefore, we drew on the reported categories of meaningful activities and their descriptions to extract equivalent possible types of soft goal of people living with

dementia associated with the 3 themes. Two additional types – *engaged in creative activity achieved* and *engaged in personal finances achieved* – were added to these soft goal types from other sources. After the workshops with professional carers, the model was composed of 17 different types of soft goal that described outcomes associated directly with the completion of common meaningful activities. Examples of these extracted soft goal types are depicted graphically in Fig 6.

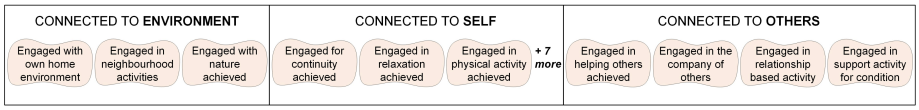

Fig 6. Examples of goal types achieved directly by the successful completion of types of meaningful activities, structured by the connectedness model reported in [10]

5.4 The modelled contribute-to links between quality of life soft goal types

The literature review and validation workshops revealed that most modelled contributes-to links were *Help* rather than *Make* links. The achievement of most meaningful activity or quality of life soft goal types contributed positively to achieving other quality of life soft goal types, but on its own, each contribution was insufficient to achieve the quality of life soft goal type. Only a small number of contributes-to links were *Make* links, for which achievement of a meaningful activity or quality of life soft goal type was sufficient to achieve a quality of life soft goal type. In cases where the *Some+* contributes-to links were modelled, we took consensus across the workshops to remove each link or change it to a *Help* contribution.

Example contributes-to links of both types are shown in Fig 7, which depicts *Make* contributions arising from achieving the soft goal type *engaged in intellectual brain activity achieved*. The model describes that engaging in *intellectual brain activities* is sufficient, on its own, to *maximise cognitive health*. By contrast, maximizing cognitive health is not, on its own, sufficient to maximize *quality of life*.

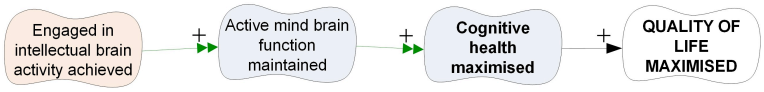

Fig 7. Flattened representation a goal contribution thread through the new quality of life model showing the contribution of having engaged in intellectual brain activity

5.5 Modelled tradeoffs between quality of life soft goal types

The validation workshops also uncovered trade-offs between types of soft goal that were true in most care contexts. Trade-offs were needed because the *EnableSelfCare* toolset is required to support someone with dementia to evaluate the impact of their activities on quality of life over a given time period. Understanding trade-offs would inform their decision making about qualities to achieve and activities to plan. Whilst professional carers reported that there was scope to achieve most quality of life soft goal types without tradeoffs, some tradeoffs did hold for most cases of people living

with dementia. One tradeoff, which is depicted in Fig 8, was between the soft goals *sense of freedom achieved* and *sense of safety achieved*. Other soft goal trade-offs that were modelled were between *activity* and *relaxation*, *support/nurture* and *independence*, and family *involvement* and *respite*.

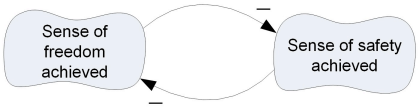

Fig 8. A two-way trade-off expressed using contributes-to links between types of soft goals

5.6 Modelled meaningful activity types contributing to quality of life

The types of meaningful activities that were modelled were extracted from examples in the literature (e.g. [8]) and classified into domains to link to modelled soft goal types. Classes such as *physical*, *spiritual*, *intellectual* and *social* were refined by sub-classes e.g. *tennis* as a subclass of *sport*, as shown in Fig 9. Other sub-classes of meaningful activities were then elicited from the validation exercises. Once the classification was stable, additional data from an additional published source – the *Compendium of Physical Activities* [32] – was analyzed in order to generate additional meaningful activity types and task attributes such as such as how much physical energy needs to be expended on typical activity types, to enable comparisons when making decisions.

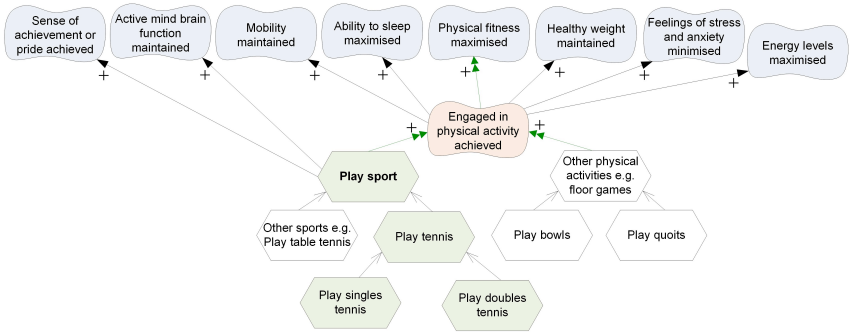

Fig 9. Mapping classified meaningful activities to the quality of life soft goal types

5.7 The Resulting Quality of Life Goal Model

The resulting descriptive version of the quality of life goal model was composed of 63 different soft goal types and a larger number of contributes-to links between these soft goal types, see Fig 10. The model also described another 744 different task types representing types of meaningful activities that contribute to the modelled quality of life soft goal types, but these are not shown in Figure.

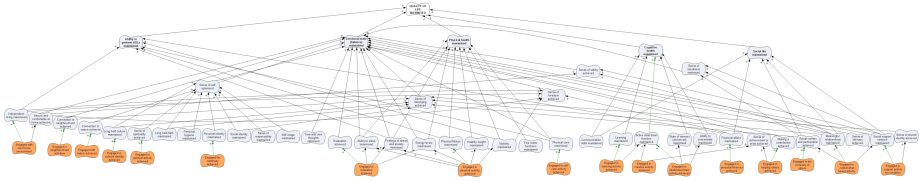

Fig 10. The final version of the quality of life goal model, showing types of soft goal sought by people living at home with dementia, accessible at [33]

This descriptive model of quality of life goal was subsequently transformed into a computational version in the *EnableSelfCare* toolset. This new version receives as inputs data about the degree of completion of meaningful activities of different types, then computes and propagates values representing the degree of achievement to quality of life goal types, to provide feedback on qualities of life being achieved and alternative activities to achieve better the quality of life goal types not being achieved. We look forward to reporting on this computational model in future publications.

6 Insights and Lessons

As well as produce the new model of quality of life goals for people living with dementia, the application of the goal modelling provided a series of unexpected insights by the researchers and professional care practitioners about the social care literature.

The conceptual analysis confirmed that no single existing social framework (e.g. [2, 6, 8] provided complete guidance to describe all of the quality of life goals that were described in the model. Instead, the model was a synthesis of overlapping goals identified in and extracted from different frameworks. Indeed, our conceptual analysis using the goal modelling language [31] was essential to undertake a cost-effective synthesis of quality of life goals from different frameworks, based on the identification of overlapping goals and associations between goals. Moreover, the validation workshops with the professional carers revealed that our codification of the informal using the *i** goal modelling language based on available literature had been relatively accurate, and that the model omissions reflected the gaps between the partial frameworks. This outcome revealed that reviewing and interpreting a complex and inconsistent literature in order to produce a complex goal model in a new discipline can be an effective means of undertaking research.

One possible reason for the partial guidance offered by the reviewed social care frameworks (e.g. [2, 6]) was the need for simple forms of guidance that carers appeared to require. Most carers were not educated to degree level and had little time to read or learn guidance to undertake care work. Indeed, many were not professional, and had received limited training. Therefore, most published guidance appeared not to incorporate or report underlying complex concepts, even though those concepts were important for understanding and delivering dementia care. By contrast, our reported use of the goal modelling language separated the description of complex phenomena from the computational use of the model to generate simpler guidance when needed – a separation new to dementia care guidance and to many people re-

sponsible for caring for older people. Managing the lives of people with dementia and other chronic diseases remains a complex problem lacking solutions. To understand this complexity, the authors used a new method to describe this complexity – a method from information systems engineering research.

Furthermore, model validation in the workshops often externalized care knowledge that was semi-tacit. This new externalization of care knowledge, in turn, encouraged the care professionals to reflect on their care practices. For example, the professionals in the workshops reported that the model supported them to contextualize their care expertise. One said: "*To us, we just do what we do. You know, we don't class it as a job. So looking at that now [the model] you don't realize what you do looking at it on paper. You think oh gosh, do I do that, do I do that? Ooh, you know isn't it. We don't realize a lot of it*.". Whilst the care professionals had knowledge of quality of life frameworks and experience with different types of meaningful activity in their work, they had not seen a framework that connected both. As a consequence two commented: "*It's like a flow isn't it*" and "*I found it surprising that something down there can come to up there actually*". Although the use of conceptual modelling visualizations is now familiar in business analysis, engineering and even healthcare, the use in dementia care appeared to be new, especially to externalize and model concepts associated with quality of life. The modelling experience revealed the benefits of applying information systems engineering methods in new domains.

Finally, use of the *i** goal modelling language was a critical enabler for the authors to design and implement a new computational model of quality of life goals as part of the *EnableSelfCare* toolset. We are beginning to evaluate the completeness and accuracy of this computational model.

7 Conclusions

This paper reports the use of the *i** goal modelling language from information systems engineering to understand, model and synthesise existing frameworks of quality of life of people living with dementia. It presents a new goal model of quality of life for the development and implementation of automated reasoning capabilities.

The authors believe that this research can inspire and guide other researchers to explore new avenues and opportunities for the use of information systems engineering methods. For example, the goal modelling languages can be applied to model and analyse the quality of life goals of people living with other chronic conditions such as Parkinson's and different forms of cancer. And understanding and support the qualities of the lives of citizens have become increasingly important to governments, such as the *Good Society Framework* [11] applied by a previous UK government. Again, conceptual modelling can be applied to support such work. As engineers, we have responsibilities to deploy our knowledge and skills for the wider good.

Acknowledgements

This work is supported by the EPSRC-funded SCAMPI project Grant EP/P010024/1.

References

1. Bhattacharya K., Gerede C., Hull R., Liu R., Su J.: Towards Formal Analysis of Artifact-Centric Business Process Models. In: Alonso G., Dadam P., Rosemann M. (eds) Business Process Management, LNCS, vol. 4714. Springer Berlin, Heidelberg, pp. 288-304 (2007).
2. Bowers H., Bailey G., Sanderson H, Easterbrook L., Macadam A.: Person Centred Thinking with Older People: Practicalities and Possibilities. HSA Press, Stockport, UK (2007).
3. Cahill S. Macijauskiene J., Nygard A., Kaulkner J., Hagen I.: Technology in Dementia Care. Technology and Disability 19(2/3), pp. 53-54 (2007).
4. Chen L. Babar M.A.: A systematic review of evaluation of variability management approaches in software product lines. Information and Software Technology 53(4), pp. 344-362 (2011).
5. Chiasera A., Creazzi E., Brandi M., Baldessarini I., Vispi C.: Continuous Improvement, Business Intelligence and User Experience for Health Care Quality. In: Krogstie J., Reijers H. (eds) Advanced Information Systems Engineering. CAiSE 2018. LNCS, vol. 10816, Springer, Cham, pp. 505-519 (2018)
6. Cook A., Miller E,: Talking Points Personal Outcomes Approach: Practical Guide. JIT: Edinburgh (2012).
7. Cowans G., Campbell J., Alm N., Dye R., Astell A., Ellis M.: Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. Proceedings CHI'04 Extended Abstracts, ACM Press, pp. 825-836 (2004).
8. Han A., Radel J., McDowd J. Sabata D.; Perspectives of People with Dementia About Meaningful Activities: A Synthesis. American Journal of Alzheimer's Disease and Other Dementias 31(2), pp. 115-123 (2016).
9. Harmer B., Orrell M.: What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. Aging & Mental Health 12(5), pp. 548-558 (2018).
10. Hodge J., Balaam M., Hastings S. Morrissey K.: Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. Proceedings CHI2018 Conference, ACM Press, Paper No. 514 (2018).
11. Jordan P.: The Good Society Framework. Accessed at http://www.patrickwjordan.com/15/business-psychology-models, 23/11/2018
12. Karakostas A., ILazarou I., Meditskos G., Stavropoulos T., Kompatsiaris I., Tsolaki M.: Sensor-based in-home monitoring of people with dementia using remote web technologies. Proceedings of International Conference on Interactive Mobile Communication Technologies and Learning (IMCL), Thessaloniki, 2015, pp. 353-357 (2005).
13. Lawton M.: Quality of Life in Alzheimer Disease. Alzheimer Disease and Associated Disorders 8(3), Raven Press Ltd., New York, pp. 138-50 (1994).
14. Lazar A., Edasis C., Hazelrig A.. Supporting People with Dementia in Digital Social Sharing. In Proceedings CHI2017 Conference, ACM Press pp. 2149-2162 (2017).
15. Lockerbie J., Bush D., Maiden N.A.M., Blom H. & Everdij M.,: Using i* Modelling as a Bridge between Air Traffic Management Operational Concepts and Agent-Based Simulation Analysis. Proceedings 18th IEEE International Requirements Engineering Conference, IEEE Computer Society Press, pp. 351-356 (2010).
16. Lockerbie J., Maiden N.A.M., Engmann J., Randall D., Jones S. & Bush D.: Exploring the impact of software requirements on system-wide goals: a method using satisfaction arguments and i* goal modelling. Requirements Engineering Journal (17)3, pp. 227-254 (2012).

17. Munteanu C., Fernandez-Lozano C., Mato V., Salvador A., Fernández P., Álvarez-Linera J., Antoni J., Pazos A.: Classification of mild cognitive impairment and Alzheimer's Disease with machine-learning techniques using H Magnetic Resonance Spectroscopy data, Expert Systems with Applications 42 (15–16), pp. 6205-6214 (2015).
18. Palacios-Ceña D., Gómez-Calero C., Cachón-Pérez J.M., Velarde-García JF., Martínez-Piedrola R., Pérez-De-Heredia M.: Is the experience of meaningful activities understood in nursing homes? A qualitative study. Geriatric Nursing 37(2), pp. 110-115. Elsevier (2015).
19. Nolan M., Brown J., Davies S., Nolan J., Keady J.: The Senses Framework: Improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2. Sheffield Hallam University (2006).
20. Prince M., Wimo A., Guerchet M., Ali G, Wu Y. Prina M.;. World Alzheimer Report 2015, The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends. Alzheimer's Disease International, London (2015).
21. Ready R., Ott B.: Quality of Life measures for dementia. Health and Quality of Life Outcomes 1(11), (2003).
22. Riepe M., Mittendorf T., Förstl H., Frölich L., Haupt M., Leidl R., Vauth C., von der Schulenburg M.: Quality of Life as an Outcome in Alzheimer's Disease and other Dementias - Obstacles and Goals. BMC Neurology 9(47) (2009).
23. Sutcliffe A., Sawyer P, Stringer G., Couth S., Brown L., Gledson A., Bull C., Rayson P., Keane J., Zeng X., Leroi I.: Known and unknown requirements in healthcare. Requirements Engineering Journal, pp. 1-20, https://doi.org/10.1007/s00766-018-0301-6 (2018).
24. Thiry E., Lindley S., Banks R., Regan T.: Authoring personal histories: exploring the timeline as a framework for meaning making. Proceedings CHI 2013 Conference, ACM Press pp. 1619-1628 (2013).
25. Vaarama M.: Care-related quality of life in old age. European Journal of Ageing 6(2), pp. 113-125 (2009).
26. Veeramuthu A., Meenakshi S., Manjusha P.: A New Approach for Alzheimer's Disease Diagnosis by using Association Rule over PET Images, International Journal of Computer Applications (0975 – 8887) 91(9), pp. 9-14 (2014).
27. Wallace J., Thieme A., Wood G., Schofield G., Oliver P.: Enabling self, intimacy and a sense of home in dementia: an enquiry into design in a hospital setting. Proceedings CHI'2012 Conference, ACM Press, pp. 2629-2638 (2012).
28. Wilhelmsen K., Andersson C., Waern M. Allebeck P.: Elderly people's perspectives on quality of life. Ageing and Society 25(4), pp. 585-600 (2005).
29. Woods B, Spector A., Jones C., Orrell M., Davies S.: Reminiscence Therapy for Dementia. Cochrane Database Syst. Rev. April 18(2), CD001120 (2005).
30. World Health Organization, Constitution of WHO: Principles. http://www.who.int/about/mission/en/. Accessed 23/08/2018.
31. Yu E, Giorgini P., Maiden N., Mylopoulos M: Social Modeling for Requirements Engineering. MIT Press, Cambridge, MA (2010).
32. Ainsworth B., Haskell W., Herrmann S., Meckes N., Bassett D., Tudor-Locke C., Greer J., Vezina J., Whitt-Glover M., Leon A.: 2011 Compendium of Physical Activities: A Second Update of Codes and MET Values. In Medicine and science in sports and exercise. 43(8), pp. 1575-81 (2011).
33. SCAMPI website, http://scampi.city.ac.uk/files/QoL_Model_Winter_2018_CAiSE.pdf, (2019)