Modelling the quality of life goals of people living with dementia

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Highlights

- Conceptual modelling of goals contributing to quality of life with dementia
- Co-designing a model of quality of life with experienced care professionals
- Automated reasoning about older people's daily goals and activities

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. This model was then refined in co-design workshops with experienced professional care workers. The conceptual model was used to construct automated reasoning capabilities in a new digital toolset that people with dementia can use for life planning.

Keywords

Dementia, quality of life, interactive toolset, goal modelling

1. Introduction

Information systems engineering theories and methods are well established in their disciplines. Outcomes from basic and applied research results that are reported have transformed into maturing information systems engineering practices. Examples of these practices include business modelling formalisms [Bhattacharya et al. 2007], product variability and configuration management mechanisms [Chen & Babar 2011], and goal modelling techniques [Yu et al. 2010]. 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 analyse more traditional types of information systems in domains such as air traffic management systems [Lockerbie et al. 2010] and person-centric healthcare [Chiasera et al. 2018]. By contrast, there has been

relatively little cross-discipline use made of the research and practices in domains as diverse as marketing and the curation of art collections. 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 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. It has become as a major societal challenge due to the increased ageing of populations, especially in more advanced economies. The economic cost of dementia worldwide has been estimated to be US$818 billion annually, rising to US$2 trillion by 2029 [Prince et al. 2015].

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 [Riepe et al. 2009] 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 [WHO 2018]. 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. [Wilhelmsen et al. 2005]), a single and accepted model of quality of life is still missing. Furthermore, many people with dementia also have co-morbidities – other illnesses such as Parkinson's disease, diabetes and anaemia – that add to the barriers to a defined quality of life.
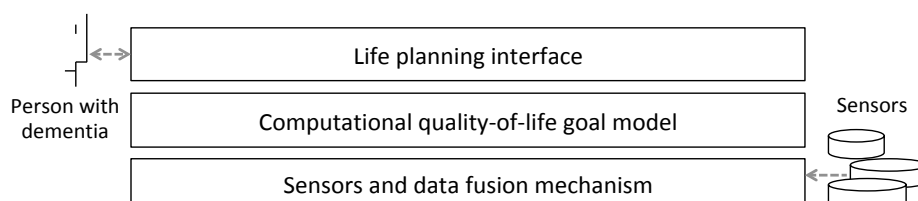
Over the last 20 years, different activities of daily life with the potential to overcome barriers and maintain aspects of quality of life have been reported widely. Better-known general examples of these activities include the person listening to their favourite music and reminiscing about past experiences [Woods et al. 2005]. 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.

Most of the care support for people living with the dementia is based on social care research. This research has led to different quality of life frameworks to help people with dementia understand and communicate their life preferences and needs. Most of the frameworks focus on selected aspects of the person's preferences and needs, such as framing a person's quality of life choices [Lawton 1994], describing personal outcomes [Bowers et al. 2007] and documenting preferred meaningful activities [Palacios-Ceña et al. 2005]. Moreover, all were developed for care workers 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 simplest digital tools. Indeed, guidance is normally reported using informal language.

For example, practical guidance for care professionals for describing personal outcomes [Nolan et al. 2006] is presented as simple natural language statements. For example, quality of life needs are expressed using statements such as *I feel safe* and *I live as I want*, and quality of life changes are expressed as *my skills are improved* and *my mobility is improved* [Lawton 1994]. 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 potential ambiguities, inconsistencies and overlaps between concepts (e.g. between *I see people* and *I belong to a community*).

Although experienced carers 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 were 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, the 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.

The current format of most 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. Our motivation for applying these theories and methods was to guide the development of a new digital toolset for use by people living at home with dementia to plan to improve the qualities of their lives. The person would interact with the toolset using a simple interface to describe the quality of life goals that s/he sought to maintain or achieve, and the meaningful activities that s/he desired to undertake. These descriptions were 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 generated descriptions of the person's activities from data collected from these sensors – descriptions that provided input data to a computational model of quality of life. The toolset architecture is depicted in Figure 1. The computational model used these descriptions to infer whether the quality of life goals were being achieved.

Fig 1. Simplified architecture of a new toolset to support people living with dementia to improve their quality of life

In this paper we report the use of an advanced goal modelling method from information systems engineering to develop a conceptual model of quality of life from existing social care frameworks that was sufficiently precise to design the toolset's operational software.

The rest of this paper is in 5 sections. The next reports the material and methods used to develop the conceptual quality of life goal model using a design science approach. Sections

3 and 4 describe the goal modelling language that was selected to provide the theoretical underpinnings for modelling quality of life and the results of the modelling and co-design activities. The paper ends with a discussion of the resulting quality of life goal model and the approach used to develop it and conclusions for using information systems engineering methods other non-engineering domains.

2. Material and methods

The key research challenge was to design a model of quality of life that was sufficiently precise to enable the model to implemented as operational software. To frame the challenge, the quality of life goal model was developed to be a description of the requirements, i.e. the quality of life needs, that people using the toolset would have. Jarke & Pohl [1993] classified 4 types of information system requirement based on the 4 system worlds: the system world, which corresponded to the toolset itself; the usage world, which corresponded to social and individual aspects of toolset use; the subject world, which described referential domain aspects, and; the development world that corresponded to development of the toolset. Using this classification, the quality of life goal model was developed to describe the subject world – a desired quality of life with dementia – and parts of the usage world – activities that people will undertake based on recommendations inferred from the model.

Furthermore, the quality of life goal model was developed to describe all of the types of goals and activities that would hold for most people living with dementia. Therefore, it described types of goal, for example *engaged with neighbourhood*, rather than instance-level goals such as *involved in the local Finchley neighbourhood*, and types of activity, such as *take part in neighbourhood watch*, rather than instance-level descriptions such as *take part in the North Finchley neighbourhood watch*.

2.1 The design science approach

A design science approach was adopted to develop the quality of life goal model. Design science is effective for addressing wicked and unsolved problems in unique or innovative ways [Hevner, March, Park, & Ram, 2004]. It develops solutions to problems, then tests these solutions to determine the how well they work. Solutions are developed iteratively, so that each can then be adapted and re-tested to gather more data.

The development of a precise goal model of quality of life with dementia was a wicked and unsolved problem. No such model had been reported, either in the research literature or in practice guidance. Therefore, different solutions – versions of the quality of life model – were developed. Each of these solutions was tested to produce data with which to explore sources of information in different literatures, structure the discovered information in different ways, refine the modelling semantics used, and generate new versions of the goal model.

Not all valuable knowledge about quality of life was assumed to be described in the published social care frameworks. Therefore, a co-design approach with experienced professional care workers was also used to refine the developed quality of life model. In co-

design approaches, stakeholders other than designers undertake the design work and make creative contributions to the formulation and solution of a problem. The experienced professional care workers were assumed to have valuable knowledge about quality of life participated in co-design workshops to refine the goal model.

2.2 Reviewing existing social care frameworks

To develop a first version of the new quality of life goal model, we conducted a structured review of academic literature on quality of life in dementia care and the wider social care domain. This structured review investigated topics that included quality of life models and approaches, activities of daily living, and meaningful activities. At stages, to direct the review, we consulted about the review findings with leading academics (e.g. a Professor of Adult Nursing who specialised in dementia) and practitioners (e.g. a Dementia Care & Wellbeing Consultant) in dementia care. Based on these consultations we sometimes reviewed other literatures, including personal outcome approaches in care settings which related to maintaining or improving wellbeing. 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 such as goal tree diagrams. When it was assessed to be sufficiently complete, the informal model was described formally using the *i** goal modelling language.

2.3 The language for modelling quality of life

A modelling language was needed to represent knowledge about goals related to quality of life with dementia more precisely than with existing social care frameworks. In order to describe each older person's subject and usage worlds, this language was required to represent both the complex states that people living with dementia sought to achieve and the diverse types of activities that contributed to them achieving these states.

Goal modelling has been the focus of research in both human-computer interaction (e.g. *Task Knowledge Structures* [Johnson et al. 2001] and *Concur Trees* [Paterno et al. 2011]) and software engineering (e.g. *KOAS* [van Lamsweerde 2009] and *i** [Yu et al. 2010]). However, the literature about the different types of goal models revealed different modelling emphases for different purposes. The languages from human-computer interaction focused more on the representation of task knowledge in what Jarke & Pohl [1993] described as the usage world, i.e. knowledge about what people do to achieve goals, whereas the languages from software engineering also represented goal states to be achieved by tasks in the subject world [Jarke & Pohl 1993]. Therefore, our method selected a software engineering language to represent goal states associated with quality of life.

The different languages from software engineering were developed to model goals related to different types of system-supported activities. Whereas the KAOS language represents more precise goals that software systems are designed to attain, the *i** language was developed to represent the goals of different heterogeneous actors, both human and organisational, and how these actors attain and achieve these goals by undertaking different tasks. It described how these actors attained their goals to different degrees. It had been applied to analyse goals and associations in complex systems in, for example,

healthcare monitoring systems [Lockerbie at al. 2010]. This explicit representation of health-related goals that can be more or less achieved by the completion of different tasks led to the selection of *i** to model quality of life goals.

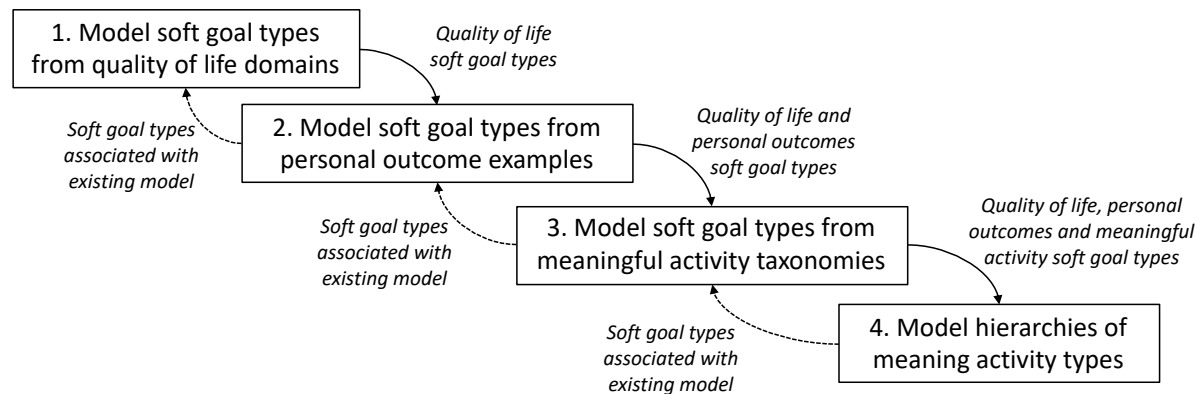## 2.4 Developing the new model of quality of life

The literature review revealed a very wide range of treatments of quality of life in disciplines such as health and nutrition. Therefore, we restricted the review to quality of life of people living with dementia. Lawton [1994] 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 [Ready & Ott 2003]. Therefore, the first version of the goal model and the types of goal that it described was based on Lawton's framework [Lawton 1994].

Although Lawton's framework identified important elements with which to structure the goal 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 [Brooker 2007]. After consultations with the care academics and practitioners, we also conducted a review of the personal outcomes literature (e.g. [Bowers et al. 2007]) associated with person-centred care practices. Personal outcome goals are, by definition, specific to individuals [Cook & Miller 2012], so the review revealed numerous examples of individual 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.

To associate these 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 (e.g. [Han et al. 2012]). 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 process used to develop the goal model is summarised graphically in Fig 2. In the first step the process elicited and modelled a small number of types of soft goal associated with qualities of life that all people living with dementia would seek to achieve [Lawton 1994]. In the second it elicited a larger number of types of soft goal that were extracted from goal examples from the personal outcome frameworks (e.g. [Bowers et al. 2007, Cook & Miller 2012]). These new soft goal types were then associated with the soft goal types modelled in the first step, and new associations between these soft goal types were discovered and

added to the model. In the third step the process extracted types of soft goals from documented meaningful activities (e.g. [Han et al. 2016]), and these soft goal types were also associated in the model with the soft goal types extracted from the literature on personal outcomes. The fourth step the process extracted meaningful activity types associated with achieving quality of life, and structured them in types hierarchies. It then associated each of these activity types with one or more soft goal types that the completion of the activity types contributed to, based on the available literature.

Fig 2. The basic four-step process used to develop the quality of life goal model from literature about social care frameworks

2.5 Co-designing aspects of the quality of life goal model

Not all valuable knowledge about quality of life was assumed to be described in the published social care frameworks. Therefore, the method also sought direct human input to design versions of the model. People living with dementia were considered to be one possible source of this valuable knowledge. Indeed, most methods that design for dementia encourage participation of people living with the condition (e.g. [Treadaway et al. 2019]). However, as well as cognitive impairments that inhibit reasoning and communication, most people living with dementia only experience the condition from their own, rather than the more general perspectives that we were seeking for the model. Therefore, co-designing the model using inputs from people living with dementia was rejected. By contrast, experienced professional care workers often do have valuable knowledge about meaningful activity types and their impact on quality of life. Many regularly need to make decisions about many different people living in diverse circumstances using their knowledge of quality of life goal meaningful activities that can achieve these goals. Therefore, our method also sought to capture this care knowledge and incorporate it into the model. A key challenge was how.

Established methods such as shadowing and observing the care workers were rejected due to the difficulties associated with gaining access to people's homes and debriefing the busy care workers afterwards. More direct methods such as interviewing the care workers were also rejected due to the potential difficulties of verbalizing complex care goal types and associations. Likewise, verbal techniques for eliciting domain expert knowledge such as laddering, card sorting and repertory grids (e.g. [Cordingsley 1992, Rugg et al. 1992]) were judged to be insufficient for capturing the networks and different types of association that exist between large numbers of types of goals and activities. By contrast, physical artefacts from co-design approaches such as context maps and customer journey maps (e.g.

[Stickdorn & Schneider 2010]) have been developed to support people with domain knowledge to model complex networks and associations.

Therefore, physical prototypes of the quality of life goal model were used to enable the care workers to externalise their own care knowledge by adding, editing and removing elements to the physical model themselves, rather than by verbalising complex knowledge to researchers directly. At different points in the process outlined in Figure 2, experienced professional domiciliary carers contributed their knowledge about care to 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 types of goal and links between these goal types. This paper reports the method and results from the first 3 workshops.

2.5.1 Participants

The participants were 12 paid domiciliary care workers from the Alzheimer's Society in the United Kingdom who made 1 or more weekly visits to care for people living at home with dementia. All were selected because of their experience and practical knowledge of selecting and adapting meaningful activity types that contributed to achieving the desired qualities of life of the individuals in their care. The care workers had an average of 10 years experience of caring for people with dementia, and the most experienced had 22 years of care experience. Each workshop involved a care worker with at least 7 years of relevant care experience. Each care worker participated in one design workshop.

2.5.2 The physical prototypes

After experimenting with different types of object, the physical model was constructed with small pieces of card of different colours to represent model goal types, pieces of string to represent links between goal types, and wooden pins to attach the string to the cards. The string and wooden pins were selected to enable care workers to change the model quickly and easily. The cards and string were pinned to white foam boards, and laid out to replicate the quality of life model. Each physical model was then positioned horizontally on a table so that care workers standing next to it could reach all parts of it.

The complete model was deemed too large to co-design effectively during a single workshop. Therefore, the model was divided into 3 overlapping but coherent parts. Each part was bounded using the reported different forms of connectedness for categorizing types of meaningful activities reported in [Harmer & Orrell 2018]. Each model part described approximately 50 goal types and their links related to connecting to *oneself*, to *others*, and to *one's environment*. Examples of physical representations of the model parts are shown in Figure 3.

Figure 3. The physical prototype of one part of the quality of life goal model parts as set-up at the start of a co-design workshop

2.5.3 The co-designing procedure

Each co-design workshop involved 4 care workers and 2 researchers, and lasted approximately 2hr30m. Each began with introductions, a short video that described the project and the presentation of a single slide that described how a software implementation of the model might be used. The care workers were encouraged to ask questions. Each workshop was then a sequence of 4 exercises:

(1) *Share experiences*: the care workers were asked to report their experiences of changing one or more meaningful activities in a person's life that impacted positively on the quality of that life, to generate common ground for discussion between the 4 care workers;

(2) *Brainstorm meaningful activity types*: the care workers stood in front of the physical model with only the leaf-node goal types visible. They were asked to recall types of meaningful activities undertaken with the people in their care, and associate these types of activities with the goal types in the model that were visible. When no relevant goal type was visible, the care workers were instructed to add new goal types by documenting them on different coloured cards and adding the cards to the model. Each care worker documented each meaningful activity type on a new card and pinned it to the board. The care workers were then encouraged to walk through and verbalise each meaningful activity type's impact on each individual visible goal type;

(3) *Explore impacts of meaningful activity types*: the complete physical model was revealed to the care workers. One of the researchers explained that the model had been generated from existing frameworks and required inputs using their expertise to increase its completeness and correctness. To demonstrate how different types of meaningful activities might impact on different goal types, the researchers picked 2 example activity types and walked through the model to report different impacts on each on the modelled goal types. The care workers were invited to agree or challenge each impact, and to amend and/or add new goal types. The care workers repeated this process with different meaningful activity types that each of them had incorporated into the model;

(4) *Explore goal type constraints and trade-offs*: the care workers were asked to report other factors that would affect a person's achievement of his or her goal types. Examples of these factors included constraints on the person that might stop

meaningful activities being undertaken, trade-offs between goal types, and types of goal more important to people's quality of life.

2.5.4 Focus groups

After each workshop, the authors held a short focus group to elicit feedback from the care workers. Questions asked whether the model made sense and seemed natural to them, whether it reflected their expertise, what worked best in the workshop, and what could be done better next time.

2.5.5 Analysing procedure

At the end of each workshop, the changed physical prototype was recorded and all changes to it highlighted. Each change was then analysed in turn to categorize the type of model change such as *addition* or *modification* of a card or string link, and duplication between cards. The transcript of an audio recording of each workshop was then analysed to detect other potential model changes that were verbalized but not recorded on the physical model. These transcripts were also analysed to generate a rationale for each recorded model change.

3. Theory

To enable precise representation of and analyses about the goal types derived from the existing social care frameworks, the model was developed using the selected *i** goal modelling language [Yu et al. 2010]. The *i** goal modelling language and its automated analysis procedures provided the theoretical basis for the quality of life goal modelling. 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 [Yu et al. 2010].

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. The *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 health maximised*. The *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.

Fig 4 presents a simple example of the use of the *i** goal modelling language to describe what someone with dementia might want to achieve, and how it might be achieved. The example describes two soft goal types using the lozenge shape – *making a contribution achieved*, and *engaging in helping others achieved*. The soft goal types are linked by a soft goal contributes-to link. The link describes that more achievement of *engaged in helping others* contributes to more achievement of *making a contribution*. The example also describes 4 types of meaningful activity as *i** tasks using the 6-sided polygon – *participate in online support forum*, *help at a community kitchen*, *do fundraising*, and *participate in research*. Each of these tasks is linked to the soft goal type *engaged in helping other achieved*, which describes that the successful completion of each instance of each type of meaningful activity contributes to the achievement of the soft goal type.
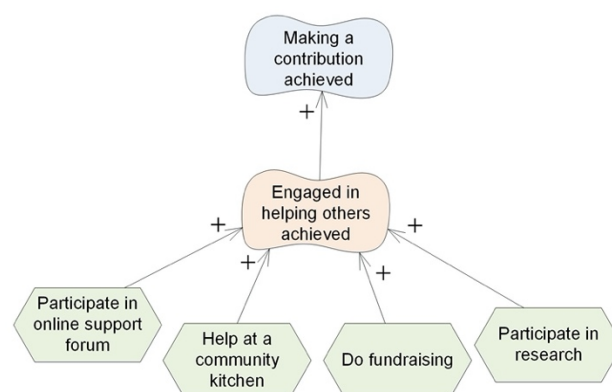

Fig 4. Example of the i* goal modelling language to describe what someone with dementia might want to achieve, and how it might be achieved

Furthermore, automated analysis procedures applied to *i** models had already been developed to allow users to explore different complex what-if scenarios, discover which goals and soft goals are achievable in different contexts, how each goal and soft goal can be achieved, and if not, why not [Horkoff & Yu 2011]. These procedures provided the baseline for the design of the computational version of the quality of life goal model.

4. Results

The 4 steps described in Section 2.4 were followed to produce a first version of all elements of the quality of life goal model. To undertake the first step, we drew on Lawton's definition of quality of life with Alzheimer's disease [Lawton 1994], which 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 behaviour*, and *a favourable balance between positive and negative emotion*. 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 5.
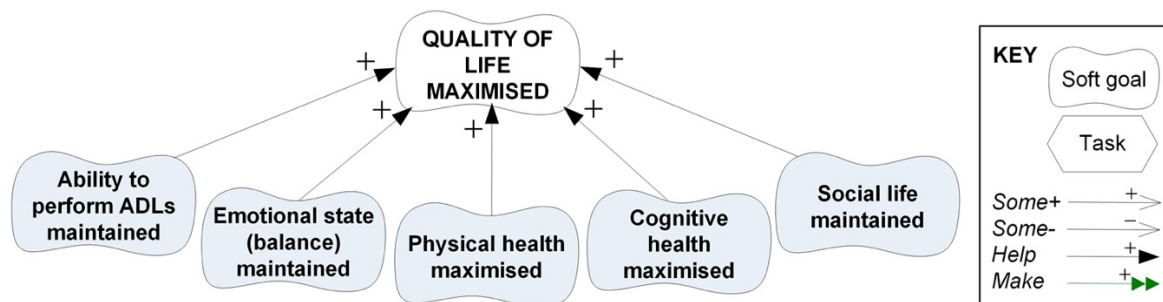

Fig 5. The soft goal types used to structure the quality of life goal model, and key of used i* graphical modelling elements. The model describes that achievement of each of the 5 soft goal types derived from Lawton [1994] contributes positively to the achievement of the soft goal type quality of life maximised

4.1 The modelled personal outcomes goal types

During the second step, the different types of soft goal generated from examples of personal outcomes in the frameworks (e.g. [Bowers et al. 2007, Cook & Miller 2012]) were described in the new quality of life goal model. After analyses of multiple personal goal examples, a total of 40 personal outcome soft goal types were added to the model. Fig 6 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*.
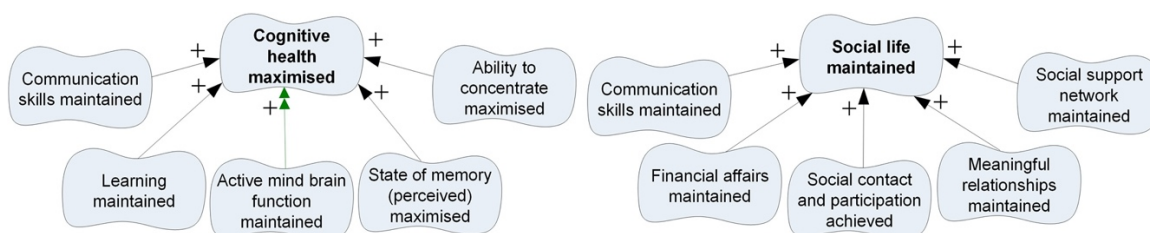

Fig 6. Different types of soft goal generated from the personal outcomes literature associated to quality of life soft goal types

Unsurprisingly, the review revealed a lack of explicit associations between quality of life goals extracted from different sources. The co-design workshops were used to discover and validate missing contribute-to links between soft goal types, and results are reported in a later section.

4.2 The modelled goal types associated with meaningful activities

During the third step, discovered types of meaningful activities included physical, social and leisure activities such as *gardening*, *reading* and *singing*. There were many factors that make activities meaningful to an individual that can relate to that person's values, beliefs, past roles, interests and routines [Harmer & Orrell 2018]. Han et al. [2016] synthesized qualitative studies of meaningful activities of people with dementia, 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. [Palacios-Ceña et al. 2015]).

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. The model was extended with 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 7.
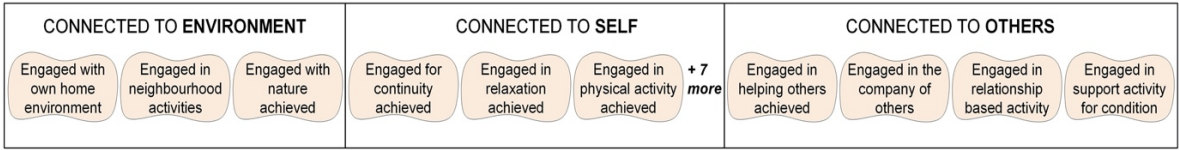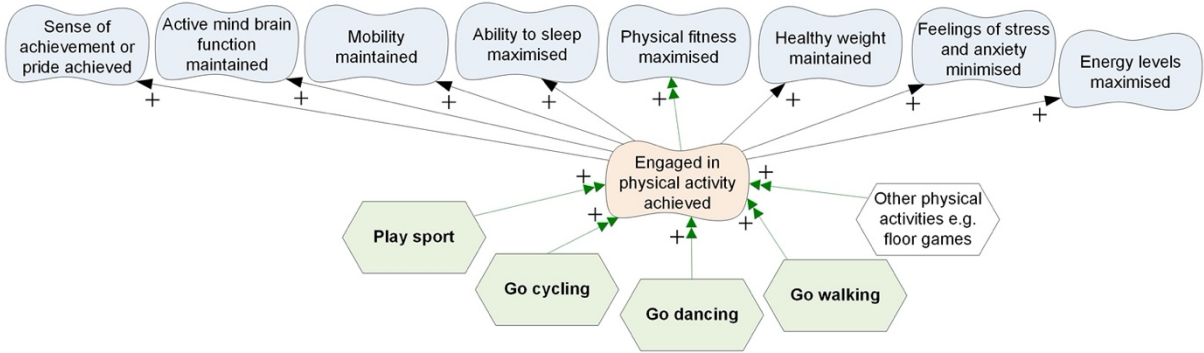

Fig 7. Examples of goal types achieved directly by the successful completion of types of meaningful activities, structured by the connectedness model reported in [10]

4.3 Modelled meaningful activity types contributing to quality of life

During the fourth step, 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. Fig 8 describes different basic types of meaningful activities, such as *play sport* and *go cycling*, which contribute to the soft goal type engaged in physical activity achieved.
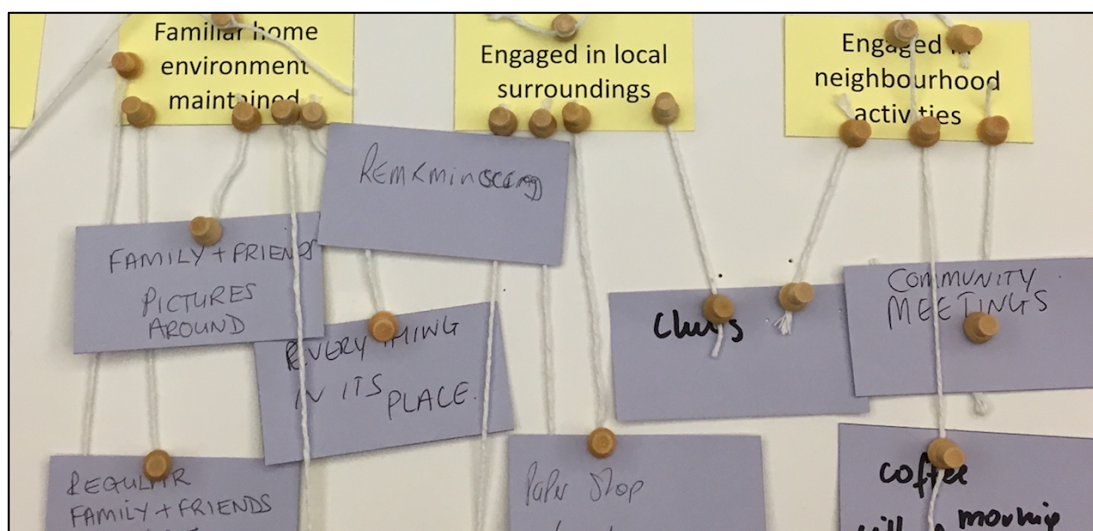
Fig 8. Examples of goal types achieved directly by the successful completion of types of meaningful activities, structured by the connectedness model reported in [10]

4.4 Changes from the co-design workshops

Each co-design workshop took place with 4 care workers and ran for the planned 2h30m. The first exercise elicited a total of 11 shared care experiences across the 3 workshops. The second generated a total of 101 documented meaningful activity types, including 3 activity types to be undertaken by the person's family members. The third exercise generated a total of 37 documented changes to the physical models as well as goal and activity types to prioritize to deliver more cost-effective care. In the fourth exercise the care workers reported trade-offs between 5 pairs of goal types and a small number of general constraints on delivering care to improve quality of life. Each of these results is reported in more detail.

During the first exercise the care workers in each workshop recounted at least 3 different care experiences. One example was: "*One very social woman had enjoyed walking, and talked to everyone in the park and café. She missed these activities and disliked being alone indoors. She was nervous about going out on her own and worried about getting lost. Therefore, the care worker went out on trips with her that enabled her to walk, and go to the park and café again. Walking was very important to her, and contributed to her social engagement*". The recounted experiences were observed by the researchers to be sufficient to provide common ground for discussions in all 3 workshops.

The second exercise generated a total of 101 meaningful activity types. Some of the 101 cards documenting these types are shown in Fig 9. Described meaningful activity types included *choirs*, *community meetings*, *ensuring that everything is in its place* and *pictures of family and friends around*.

Fig 9. A part of one physical model extended with meaningful activity types added by the care workers

All leaf-node goal types in the model were associated to at least 1 meaningful activity type, indicating that no modelled soft goal type was redundant. Most but not all of the 101 cards

were linked to a single soft goal type. By contrast, a small number of soft goal types were associated with 3 and more meaningful activity types, see Table 1. The types *engaged in nature outdoors*, *familiar home environment maintained* and *safer home environment maintained* were associated using contributes-to links to the most types of meaningful activities, indicating that more activities to achieve these soft goal types were reported.

Model goal types	Activity type cards linked to goal type
Engaged in nature outdoors	6
Familiar home environment maintained	6
Safe home environment maintained	6
Social contact in person achieved	5
Active mind maintained	4
Comfortable home environment maintained	3
Engaged in neighborhood activities	3

Table 1. Model goal types linked by the care workers to the largest number of meaningful activity types

A content analysis of the meaningful activity types documented on the 101 cards. This analysis revealed 11 pairs of cards describing the same meaningful activity types, the activity type *going to a day centre* documented on 3 cards, and individual cards described more than one type of activity. After removing duplicates and extracting single entries, the content analysis identified 83 unique types of meaningful activity that were undertaken by people with dementia. In some cases, these activity types were specializations of more general types of activities. For example, the types *singing in a choir* and *singing for the brain* were different specializations of *singing*, and the types *out for a walk* and *walking with a family pet* were specializations of *walking outside*. These specialized activity types were incorporated in new versions of the model.

The content analysis also revealed 3 types of meaningful activity that partners and other family members could have high involvement in – *communicating, personal care* and *organizing meals*, and 10 types of meaningful activity that the person with dementia and care worker together could undertake together – for example *monitoring and supporting* and *holding arm*. These attributes defining this high and joint involvement were also incorporated in new versions of the model.

During the third exercise the care workers explored how the meaningful activity types generated in the second exercise impacted on other model goal types. This impact analysis led the care workers to add 15 new goal types and 21 new links to the model, as well as reworded 1 existing goal type. No links were removed. But the exercise revealed that too many soft goal types contributed directly to *connectedness achieved* type, and this risked negating the impact of other modelled soft goal types. Therefore, this soft goal type and model structure was changed in new versions of the model to allow for direct contribution links between the personal outcome type goals and the quality of life domain goals. Again, a final version of the model is reported in a later section.

The third exercise, and subsequent results from the other 4 co-design 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.

However, the third exercise also revealed that the care workers prioritized some types of meaningful activities as having greater positive impacts on the qualities of life of people living with dementia. These included *reminiscing* and *sensorial* activities such as v*isiting a sensory garden*, *using twiddle blankets*, *exploring nature* and *developing relationships with pets*. Therefore, the model was extended so that these meaningful activity types were *Make* rather than *Help* contributes-to links to soft goal types.

During the fourth exercise, the care workers reported only 5 pairs of soft goal types that needed to be traded off during the care of most cases of people living with dementia. These trade-offs were between *rest* and *physical activity*, *freedom/personal space* and *safety*, *support/nurture* and *independence*, *time with self* and *time with others*, and *family involvement* and *family respite*. By contrast, the care workers reported that decision-making about meaningful activities often sought to balance the activities of the care worker to maintain the individual's independence. 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 trade-offs, some trade-offs did hold for most cases of people living with dementia.

During the post-workshop focus groups, the care workers reported that the modeled goal types and associations were understandable to them from their different perspectives and levels of expertise. Care workers in 2 workshops described the resulting models are "*natural*" to them, and: "*With all our experience, of all our years of experience you know exactly where they fit. At the time you're looking at it, that's right, that goes there you know*", and "*It's just putting your expertise you know and all our work knowledge, putting it on paper really*".

4.5 The final version of the quality of life goal model

The result reported here and from the other co-design workshops resulted in a new version of the quality of life goal model. The new version model was changed in 4 primary ways. First, the structure of the soft goal types in the model was changed so that all personal outcome type goals contributed directly to the quality of life domain goals, and intermediate soft goal types related to *sense of purpose achieved*, such as connected to self and connected to others were removed. The achievement of different personal outcome soft goal types contributed directly to the achievement of different quality of life domain soft goal types.

Second, the contributes-to links in the final quality of life model were refined to describe contributes-to links with *Help* rather than *Make* links in most cases. A typical example of

these contributes-to links taken from a slice of the final model are shown in Fig 10. The slice 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.
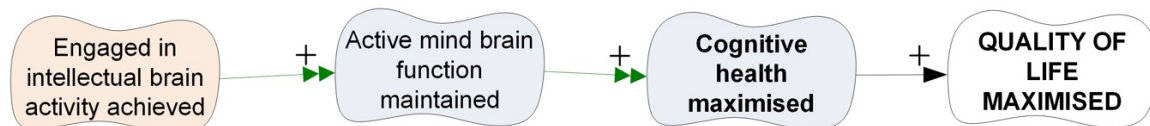

Fig 10. Flattened representation a goal contribution thread through the new quality of life model showing the contribution of having engaged in intellectual brain activity

Third, some trade-offs between soft goal types held for most cases of people living with dementia, and these few trade-offs were modelled and incorporated in the final version of the model. One of these trade-offs is modelled using the *i** language in Fig 11. It describes that the greater the achievement of the soft goal type *sense of freedom achieved*, the lesser the achievement of the soft goal type *sense of safety achieved*, and the greater the achievement of the soft goal type *sense of safety achieved*, the lesser the achievement of the soft goal type *sense of freedom achieved*.
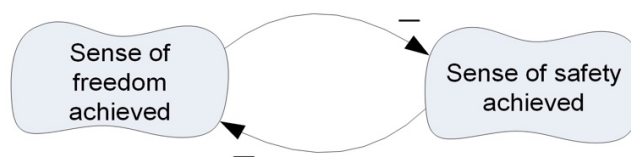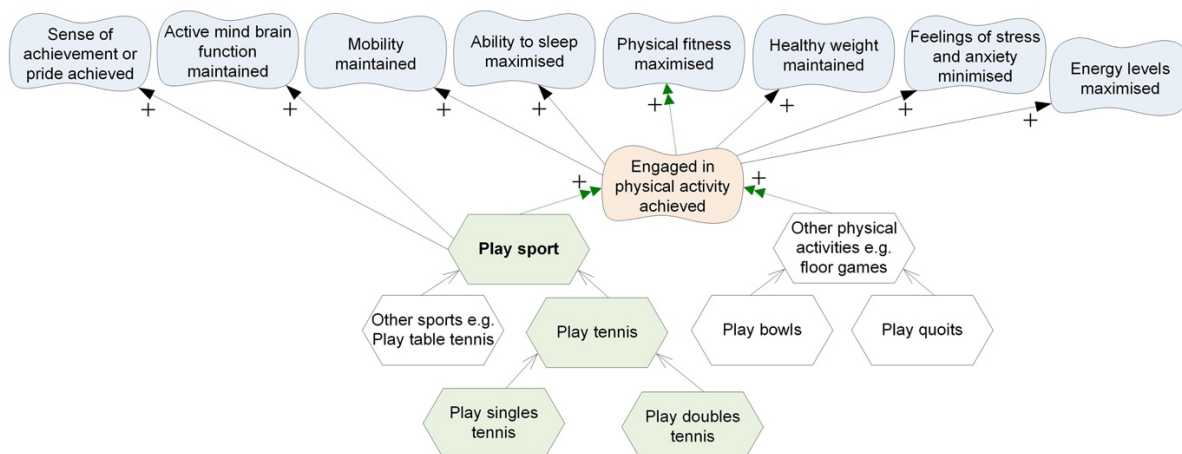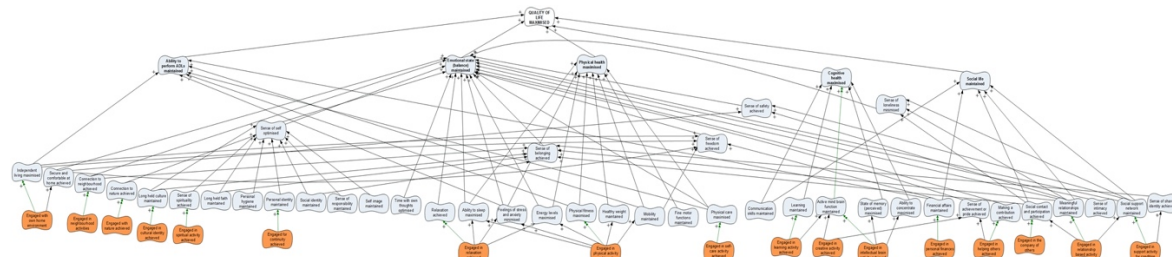

Fig 11. A two-way trade-off expressed using contributes-to links between types of soft goals

Fourth, the types of meaningful activity discovered and modelled during the co-design workshops were extended using more comprehensive information sources. After a review of different sources, the Compendium of Physical Activities [Ainsworth et al. 2011] was analysed in order to generate additional meaningful activity types and attributes such as such as how much physical energy needs to be expended on typical activity types, to enable comparisons when making decisions. The model was extended to include 744 types of meaningful activity, each modelled as a distinct and different type. Some of these meaningful activity types and their hierarchies are shown in Fig 12.

Fig 12. Mapping classified meaningful activity types to the quality of life soft goal types

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 13. The model also described the 744 different task types representing types of meaningful activity types that contribute to the modelled quality of life soft goal types, but these are not shown in Fig 13.

Fig 13. The final version of the quality of life goal model, showing types of soft goal sought by people living at home with dementia

This descriptive model of quality of life goal was subsequently transformed into software. This new version could receive 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.

5. Discussion

In contrast to the development of the new quality of life goal model reported in this paper, 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 (e.g. [Veeramuthu et al. 2014)] and magnetic resonance spectroscopy data (e.g. [Munteau et al. 2015]). To design such technologies, researchers such as [Sutcliffe et al. 2018] have reported the elicitation of new causal models of dementia diagnosis with domain experts. 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 digital technologies in social care and healthcare – opportunities that this research has sought to lay the foundations for.

More similar to the aims of the research reported in this paper, 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. [2004] 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. [2007] 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. [2012] 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. [2013] reported work in which older people made personal digital timelines using technologies designed to support the building of memory. Lazar et al. [2017] 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 [Hodge et al. 2018].

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 has been available.

As well as produce the new quality of life goal model 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. [Bowers et al. 2007, Cook & Miller 2012, Han et al. 2016] provided complete guidance to describe all of the quality of life goals that were described in the model. Instead, our new quality of life goal model was a synthesis of overlapping goals identified in and extracted from different frameworks. Indeed, our conceptual analysis using the goal modelling language [Yu et al. 2010] 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 co-design workshops with the professional care workers 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 was the need for simple forms of guidance that carers appeared to require. Most carers are not educated to degree level and have little time to read or learn guidance to undertake care work. Indeed, many are not professional, and have received limited training. Therefore, most published guidance appeared not to incorporate or report underlying complex concepts, even though those concepts are 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 responsible for caring for older people. Managing the lives of people with dementia and other chronic diseases remains a complex problem lacking sufficient solutions. To

understand this complexity, the authors used a new method to describe this complexity – a method from information systems engineering research.

Furthermore, the professional care workers also reported that the co-design process was valuable. For example, after one of the co-design workshops, one reported: "*but you picking our brains on what we do at work, you know, questioning us and asking us information whether it's right or wrong. I don't know but it's nice that you've been able to pick our brains*". After another, a care worker contrasted the design to other activities: "*This is a lovely group because we're not all overpowering. We go to some training and some staff are overpowering and you don't get your chance then to put yourself forward*". They said: "*It's interactive, you feel more engaged as a team as well.*" The physical prototype of the model was reported to be important. Comparing it to the digital version of the model, one care worker said: "*It's more hands on this way, it's really good*". Another reported: "*And not only that, I don't know, for me and kind of aesthetically I got to see how this string links to that, now that really helps me, because if that string wasn't there – you say, oh that links to that – no, I find them being linked and showing how they cross and how they link to more than one, really helped me.*" The care workers in all 3 workshops reported that the modeling supported them to contextualize their care expertise. For example, one reported: "*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.*", and another two in a different workshop reported: "*It's like a flow isn't it*" and "*I found it surprising that something down there can come to up there actually*". The feedback from these professional care workers revealed that combining information systems engineering and co-design approaches enabled the workers to articulate and share their valuable knowledge about dementia care effectively.

6. Concluding remarks

This paper reports the first 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 [Jordan 2018] 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.

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