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Supporting the Critical role of Family Carers in Wellness Management[☆]

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Abstract

Aging populations, the increased prevalence of chronic disease, and spiraling healthcare costs have led to calls for policy and technology that focuses on wellness management, preventative interventions, and decentralized healthcare. This has prompted several initiatives aimed at empowering individuals to proactively manage their wellness, including employee wellness programmes, step-tracking mobile apps, etc. However, a critical actor in this proposed new healthcare model is the family carer. These individuals are charged with managing outpatients' wellness, tracking deteriorations, providing support, and even administering routine care in order to minimize and/or delay the need for further clinical intervention. Yet for most people, 'wellness' is a poorly understood and ambiguously measured concept. Hence, family carers are often asked to rely upon personal discretion to perform their duties. This paper uses a qualitative case study based on a series of semi-structured interviews to explore how family carers manage this responsibility, the support available to them (technologically and socially), and the challenges they face. It is informed by a research model which combines activity theory and attribute substitution theory in order to make sense of how the diverse actors involved in wellness management (e.g. the family carers, the patients, other family members, clinical/non-clinical healthcare workers) communicate and coordinate. Findings suggest family carers' role in managing outpatient wellness is hindered by their inability to gather/share key wellness-related information with others involved. The study concludes by calling for better technological infrastructure linking carers with clinical professionals and more standardized information channels between various stakeholders in the caring activity.

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Keywords

Wellness; Wellness Management; Activity Theory; Attribute Substitution; Family Carers; Care Co-ordination; Healthcare Systems

Introduction

There is an increasing burden on healthcare systems, worldwide, because of the growing demands of aging populations, increased prevalence of chronic disease, and a continued movement towards cost efficient treatment options from public and private payers [1]. For example, according to the United Nations Population Fund (UNFPA) report, the number of persons over 60 years of age had increased to over 810 million by 2013 and is projected to reach two billion (one in five persons in the world) by 2050 [2]. According to an OECD study[1], healthcare budgets within OECD countries accounted for 9.3% of Gross Domestic Product (GDP) on average across these countries in 2011, while the United States spent 17.7% of GDP on health in that year. In an effort to help address the challenges of 21st century healthcare, a number of trends have emerged.

First, citizens are encouraged to take greater control over their healthcare choices [3]. This shift in focus from diagnosis and treatment to prevention and well-being requires new cultural and behavioural attitudes to lifestyle [3]. Thus, to boost wellness and encourage healthy lifestyle choices, numerous countries have begun implementing national prevention strategies [4] and many companies have introduced employee wellness programmes [5]. In addition, many information and communication technologies (ICTs) have been developed to support individual health-oriented self-regulation and behavioural change [6]. Examples include: wearable devices that track physical activity and promote increased physical fitness [7]; sleep monitors [8]; and hypertension 'dashboards' that provide information and bio-feedback to users to encourage behavior change [9].

Second, numerous pervasive e-health solutions have emerged which aim to improve healthcare delivery and reduce costs by enhancing the exchange of clinical, administrative, informational, educational and transactional data [10]. These systems are part of a wider trend towards health care systems that build on decentralized wellness monitoring and management [11]. This gives rise to increasingly complex health care systems that include a multitude of heterogeneous collaborators, such as emergency clinical staff, hospital

[1]Organisation for Economic Co-Operation and Development; Health at a Glance 2013: OECD Indicators; OECD Publishing – available at http://dx.doi.org/10.1787/health_glance-2013-en

physicians and nurses, general practitioners, clinical specialists, pharmacists, community and home care workers, and the patient themselves. Here, e-health solutions seek to leverage the ability of ICTs to: (i) collect, process, and disseminate information that supports individual decision making [12]; and (ii) create efficient linkages between collaborating parties [13].

Third, current health policy seeks to move wellness management out of the clinic and into homes and communities, particularly for older people, people with disabilities, and those who are chronically ill [14, 15]. This reflects observations that home care can reduce financial burden while preserving care quality [16, 17]. Family carers (i.e. family members providing live-in routine care to patients in their homes) continue to be the preferred and most reliable source of care in this context [18, 19]. However, while family carers often have expert knowledge of the person under their care and their conditions, their expertise is often undervalued or even ignored when decisions relating to the care recipient are being made by healthcare professionals [18].

Despite evidence that increased wellness results in reduced cost of care [20], little attention has been paid to clarifying how family carers manage patients' wellness on a day-to-day basis, nor how ICT can best support them. In light of this deficit, this paper attempts to answer the key research question "*what* is the nature of wellness management activities undertaken by family carers and *how* can ICT support these activities?" To answer this question, we leverage existing literature on Activity Theory (AT) and Attribute Substitution (AS) to build a preliminary model of carers' wellness management activities for patients. A case study approach is then described and implemented to illustrate and refine this model (some interpretation is interwoven here in order to increase the readability of the paper). Finally, we highlight the contribution of the study and suggest future research directions.

Theorizing Wellness Management

This section outlines Activity Theory (AT), including why it is applied as a primary lens for the study. The following section briefly describes Attribute Substitution (AS), a secondary complementary lens that emerged during analysis. These two theories are then synthesized and assimilated into a wellness management context in the form of a preliminary theoretical model.

Activity Theory as a lens

The origins of Activity theory (AT) can be traced back to Vygotsky [21], who observed that human being's interactions with their environment are not direct, but are mediated by cultural tools (including IT). Vygotsky

argued that consciousness and activity are interdependent and dualistic; the former arising only as one interacts with the outside world to achieve some goal. This suggests a family carer's understanding of a patients' wellness is tied to the activities that support it, as these activities provide the interface between the carer, the patient, clinical care providers, non-clinical care providers (e.g. home-care providers) and other supporting actors (e.g. other family members). Further, the tools used in these activities (including psychological tools, such as words and gestures) act not only to support these activities but also to define their structure and meaning.

Later, Engeström [22] extended AT into a social theory of consciousness, in which activities could be viewed as a collective and collaborative community pursuit, which is also mediated by: (i) the *rules/norms* that govern the relationship between an individual and their community; and (ii) the *roles/responsibilities* assumed by different actors. Thus, Engeström argued that the analysis of an activity must be considered in terms of its social context, and not just in terms of the mediating technologies. Again, this is particularly useful for family carers' wellness management activities given the range of social actors involved. This view of AT also emphasizes the importance of studying real-life use of technology as a part of unfolding human interaction in the world [23], which is essential given the dynamism and rapid evolution of the wellness management domain.

Attribute Substitution as a lens

Despite our natural tendency to understand ourselves as deliberate and rational beings, much of our decision-making relies not only on rational and reflective processes, but also on less-conscious reflexive processes [24]. The importance of each type of process varies according to: (i) the familiarity of the task [25]; (ii) the speed with which the task must be performed [26], and; (iii) the perceived computational difficulty of the task [27]. The third condition is arguably the least intuitive; as individuals may feel that difficult tasks are most demanding of conscious attention. Yet this assumption is challenged by evidence that less-conscious attribute substitution (AS) often takes the place of rational and reflective reasoning [28]. In this way, individuals faced with broad and difficult problems often unconsciously substitute them for simpler, more specific (and less challenging) problems to lower their cognitive burden. This was demonstrated by Strack et al. [29], who asked students two questions via survey: (i) 'how happy are you with your life in general?' and (ii) 'how many dates did you have last month?' The data showed little correlation when the general question was asked first, yet answers correlated at a level of over 0.6 when the order was reversed. Such substitutions require three key conditions [c.f. 28]: (i)

the target attribute is relatively inaccessible; (ii) the substitute attribute is readily available; and (iii) the capacity for reflection is limited.

These conditions are intuitively relevant to family carers, for whom wellness (like happiness) is likely to be broad and loosely bounded [30]. Hence, accessibility to the exact meaning of wellness is low, substitutable alternatives are common, and reflection is challenging (this is explained further in the following section). Perhaps more importantly, the heterogeneity of actors involved [31] suggests that available heuristics may differ between actors (note – heuristics are efficient rules which people often use to form judgments and make decisions). In this way, actors may be using the same terms (e.g. 'wellness') to describe separate issues (e.g. lack of pain, sleeping well, social inclusion). This may compromise the integrity of interactions between actors, resulting in poor communication and/or missed opportunities to prevent or treat deteriorations early.

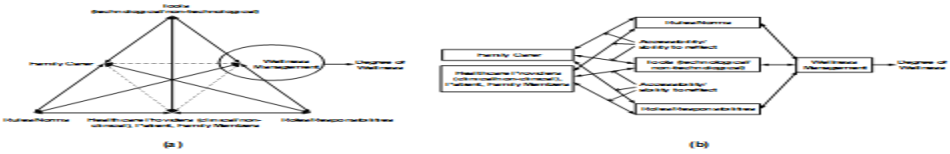
A preliminary model of wellness management

This paper models family carers' wellness management as a *mediated activity,* both technologically and socially. This model positions family carers as the *subject* of the activity; wellness management as the *object;* the patient and other clinical/non-clinical care providers as well as other family members as the *community*; and patients' wellness as the *outcome*. These central components are mediated by: (i) division of labor between actors (*roles/responsibilities*); (ii) the implicit or explicit expectations for each actor (*rules/norms*); and (iii) any technological/non-technological tools in place to help coordinate the system (*tools*). Further, from an AS perspective we propose that the effectiveness of each mediating contextual factor is impacted by the extent to which it suffers from substitution - see Figure 1.

This means that different aspects of these mediating factors may be functionally inaccessible to different actors with such inaccessibility making substitution likely. Furthermore, when inaccessible factors are substituted, they are likely to be substituted according to diverging heuristics because actors involved are likely to have different backgrounds and degrees of clinical training. For example, when a clinical professional wishes to evaluate a patient's 'energy' they might look for signs in their ease of physical movement, as this can be observed in that particular moment. In contrast, a family carer may associate the same word to describe the patients' interest in leaving the house, as they may have memorable anecdotes to support this. Such a misunderstanding presents serious consequences, because the causes (and treatments) for each may be unrelated. Moreover, the diminishing time available for interaction between different actors prohibits lengthy discussion and exploration of these substitutions, thereby decreasing the likelihood that they may reflect upon them.

INSERT Fig 1 HERE

Fig. 1. (a) Model of wellness management activity system (adapted from Engeström 1987); (b) Model redrawn to capture the vulnerabilities of mediating factors to attribute substitution



Method

This study was exploratory in nature; hence, approaches that emphasize inductive/abductive theory building and testing offer more value than deductive approaches in such circumstances [32]. For this reason, a case-study approach was adopted to thoroughly explore one suitably rich context [33], namely: family carers in the Midwest and Southwest of Ireland. These were experienced family carers who had been taking care of a family member (i.e. spouse, parent or child) with at least one long term condition and/or disability for a period of many years (typically 10+ years). This context was selected as these areas possess a strong basic health infrastructure, yet the population is sparse which places responsibility for routine care on the carers themselves. This allowed data gathering to maintain a focus on core subject matter, i.e. home care as an activity, without trivializing the role of clinical environments. Informants were selected according to a strategy of theoretical sampling, rather than representative sampling [34]. Thus, we weren't necessarily looking for even representation, we were looking for instances that were 'interesting'. No incentive was offered; instead participants were identified through word of mouth and took part based on a shared interest in the subject matter. Clinical professional and health executives were also sampled to triangulate findings and provide a rounded view of attitudes towards home care. Ethics approval was obtained from the University College Cork Social Research Ethics Committee.

Data were gathered from January 2014 to November 2014 (11 months in total) over three stages (see Table 1). At each stage, thematic analysis [35] was used to identify recurring latent patterns in the data that explained how different actors, social structures, and tools contributed to wellness management activities. For the first stage, 8 in-depth semi-structured interviews were performed with key informants, based on high-level themes identified from literature and preliminary informal discussions with carers. These interviews asked about

each of the mediating social/technological factors, as well as several open-ended questions designed to gain a deeper insight into informants' day-to-day routines.

Table 1. Data Gathering Conducted for the Study.

Technique (Tel: Telephone) (F2F: Face-to-face)	Description of Participants	No. Participants	Contact Time
Tel Interview 1, 2	National expert long-term care, Executive US National Council on Aging	1	1.5
Tel Interview 3	Senior officer, e-Health and Innovation, World Health Organisation	1	1
F2F Interview 4, 5	Head of Innovation, Carer Organisation, Ireland	1	3
F2F Interview 6	Senior manager, Care Association, Ireland	1	1
Tel Interview 7, 8	Experienced Carer and training officer, Carer Organisation, Ireland	1	2
Focus Group 1	Experienced Carers in the Midwest of Ireland	4	2.5
Focus Group 2	Clinic nurses in Carer Organisation, Midwest of Ireland	2	2
Focus Group 3	Experienced Carers, Midwest of Ireland	6	3
Focus Group 4	Clinic nurses in Carer Organisation, Southwest of Ireland	2	1.5
Focus Group 5	Experienced Carers, Southwest of Ireland	4	2.5
Tel Interview 9	Experienced long term carer A	1	1
F2F Interview 10	Experienced long term carer B	1	1
F2F Interview 11	GP with interest in elder care and dementia care	1	1.5
F2F Interview 12	Lead Geriatrician in two large hospitals, South of Ireland	1	1
		27	**24.5 hrs**

For the second stage, a number of focus groups were conducted with experienced family carers and healthcare professionals. These were similar in theme to the semi-structured interviews, but this time, participants were given more room to deviate into any subject matter they believed was relevant. See Appendix for discussion guide used during semi-structured interviews and focus groups.

For the third stage, 'venting' interviews [36] were performed with selected long-term family carers and senior healthcare professionals (i.e. participants were contacted again to discuss and validate researchers' interpretations and conclusions). All interviews and focus groups were digitally recorded and memos were taken during and after data gathering. Analysis was performed continuously by the researchers, both independently

and collaboratively. Converging interpretations ensured the reliability of findings, while divergences were identified and resolved during venting.

Findings

Attribute substitution in the management of roles/responsibilities

Informants identified several ways in which the management of *roles/responsibilities* may be impacted by attribute substitution (AS). One notable example concerned the provision of emergency care in non-clinical contexts. A family carer described how she had taken over from a hospice care worker when her husband was having a transient ischemic attack (Focus Group 1). She explained that the care worker and a hospice nurse were shocked at the calm way that she dealt with this health episode, adding "they didn't realize that this type of episode was the norm for us [herself and her family]…so whenever my husband had to go anywhere, one member of the family had to be there". Family carers, in this instance, had implemented a system of social procedures for overseeing the patient in need of care. This included rules for the movement of the patient outside of the home and processes for emergency care provision that placed significant care responsibilities on other family members. The family assumed these procedures were common and not of interest to the healthcare professionals involved, therefore, it was not presented when they were discussing the patient's wellness with them. Healthcare professionals, on the other hand, assumed that the provision of routine emergency care would be reported by the family, thus interpreted descriptions of that patient's wellness differently. Had the healthcare professionals not observed these procedures serendipitously, it is possible that they would not have become aware of the severity of the patient's condition until he was under full-time clinical care.

Many family carers felt that they were the actors best positioned to assess when the patient's condition had changed, due to the amount of time they spend with those patients. In terms of *roles/responsibilities*, this resulted in frustration when clinicians were reluctant to consult them during the design of care plans or clinical interventions. For example, one family carer was adamant that her father, who has Parkinson's disease, presents differently during the '1%' of the time while he is with his neurologist, than he does for the '99%' of the time that he is at home with her (Focus Group 5). She explained that while her father is being clinically assessed, "he can walk perfectly, has perfect speech and has no tremor…but on his way back to the car, his shuffling and tremors return". She elaborated that she felt that his ability to function so well during evaluation was a result of his fear to have his medication changed, or his freedom curtailed. The family carer, in this instance, felt that her *roles/responsibilities* included observing her father's condition in a variety of contexts over time, and that the

information that she had from those observations should be factored into decision-making. Yet, because of her inability to formally capture and relate this valuable information, the doctor appeared to substitute the essence of her communication to an expression of distress and it did not influence his clinical decision making.

Attribute substitution in the management of rules/norms

Informants also identified several ways in which AS impacts on the management of *rules/norms* around family carers. A striking example was observed when a mother caring for her terminally ill daughter explained that the doctors wanted to tell her daughter about the terminal nature of her illness (Telephone Interview 7). She protested saying that her daughter "couldn't cope with it…I can't cope with it…and at one stage a few years ago, I thought I'd have to go to a solicitor so that she wouldn't be told". The doctors felt it was their clinical duty to inform the patient. The mother felt it was her emotional duty to protect her daughter from the truth, so that she could enjoy her remaining time. Both parties were operating under different *rules/norms* and neither understood the full complexity of responsibilities for the other. Each had substituted a simpler heuristic version of those *rules/norms* that prioritized the elements of care in which they were most involved.

A second example of AS in the management of *rules/ norms* came from observations that family carers often disregarded the advice given to them by healthcare professionals. One family carer reported that a prescription given to her for her husband "went into the back of the drawer…and I never gave it to him, I'd be terrified to give it to him…he'd be zonked out" (Focus Group 1). She added "they [healthcare professionals] were dishing out tablets and they never came to see were they given". This suggests that, at an activity level, wellness management interventions were being made on the basis of both clinical rules (of which family carers had limited knowledge) and family or home-specific rules (of which clinical professionals had limited knowledge). Thus both parties were assuming asymmetrical substituted version of these rules, neither of which reflected their true complexity. Moreover, these heuristic-based understandings were not challenged because neither party had opportunity to reflect upon them.

Attribute substitution in the management of technological/non-technological tools

Discussion around *rules/norms* and *roles/responsibilities* demonstrated that AS occurs most often because the wellness related information available to particular actors in this collaborative activity is not shared with other actors involved. In the case of *technological/non-technological tools*, the study suggests that AS occurs because of an absence of information altogether. The findings indicate that this absence of information primarily results

from a lack of access to tools (e.g. Information Systems) to help them track and manage wellness. Unsurprisingly, several family carers described regularly having difficulty recalling details of health episodes and care interventions when speaking with healthcare professionals. One explained that "your memory can play tricks on you and when the doctor says 'how long is this going on?'…you don't' think it's so long, but it might be longer" (Telephone Interview 8). The inaccessibility of such information forces those family carers to assume some heuristic substitution-based estimate. This is made more problematic because the subtle nature of those deteriorations means that estimates (which are typically well-intentioned but flawed) can rarely be scrutinized or compared. Thus, even where mistakes have proven costly, family carers may inadvertently continue to offer similarly flawed estimates in the future, due to their lack of opportunity for reflection.

A further issue related to *technological/non-technological tools* arises when family carers lack the tools to capture observations in a way that is meaningful to healthcare professionals. For example, one family carer recalled standing by her husband's hospital bed one night and fighting with a doctor who wanted to discharge him. She explained that she had to spend considerable effort convincing the doctor to let him stay, even though his readings suggested he was not critical. Later that evening her husband had an attack and had to be rushed into coronary care (Focus Group 3). She added that "if he was sent home earlier that evening, my husband would have died years before he did". This instance illustrates the danger of a family carers' inability to formally capture and relate the information necessary to legitimize their subjective observations made outside of clinical care. In this case, the carer was able to pick up on symptoms but couldn't explain them in a way that was medically compelling. The doctor, who lacked this informal information about subtle changes in his patient's demeanor, was forced to substitute heuristic-based judgments based on his own observations of the patient.

Discussion and Contributions

This study explored how family carers' go about managing outpatients' wellness. A theoretical model was developed which combined Activity Theory (AT) and Attribute Substitution (AS). Our findings identify significant and troubling shortcomings regarding the infrastructure in place to support family carers, as they try to manage outpatients' wellness. In particular, findings suggest that wellness management activities are inhibited by an inability to gather and share key wellness related information in a way that is meaningful to both family carers and other clinical/non-clinical actors involved. This presents three main contributions to the area of health policy and technology.

First, by analyzing wellness management from an AT perspective, we demonstrate the social and technological complexity of the activity and the diversity of actors involved. Such complexity demands that future research or system development endeavours need to study practices in holistic and naturalistic settings, rather than reducing or compartmentalizing issues for the sake of simplicity. Such endeavours also need to exercise caution when generalizing, as family carers assume their position for prolonged periods, meaning differences between individuals may become more pronounced over time [37,38]. It further demands that researchers and developers consider the role of multiple user types, as well as the existence of both explicit and assumed roles and norms.

Second, by analyzing wellness management in terms of AS, we demonstrate that family carers' capacity to engage in wellness management is often inhibited by attribute substitution among a variety of actors, resulting from a lack of access to complete diagnostic information. This demands that policy makers, researchers, and designers place particular importance on establishing standards of communication that explicate assumptions and minimize the potential for information asymmetry between disparate actors involved in the wellness management activity. Policy makers and designers may also wish to focus on the introduction of formal processes within clinical interactions that provoke reflection in situations where heuristics are applied.

Third, by analyzing family carers' wellness management activities using both of these perspectives in tandem, we demonstrate the distinct lack of ICT support for wellness management as a collaborative and information-critical healthcare activity. This lack of health technology is surprising, given the scale of the problem, the challenges of the activity, and the non-trivial issues currently inhibiting family carers' attempts at wellness management. The growth and decreasing cost of wearable technologies capable of gathering physiological data in non-clinical contexts will certainly present opportunities for new ICT systems. Yet, no evidence was found that these technologies have penetrated wellness management activities, nor any suggestion that sufficient system-level architecture is in place for them to advance rapidly. This appears to be because the collaborative nature of the activity does not lend itself to piecemeal introduction of such technologies. In this way, the leap to large-scale ICT support may require a more profound shift in practices [cf. 39, 40]. Furthermore, despite widespread recognition that wellness involves physiological elements as well as social and psychosocial elements, no ICT support is observed which affords self-reported or perceptual measures to support the endeavours of family carers.

Strengths and Weaknesses

This study provides detailed observations of family carers' wellness management activities within an Irish context, as well as a theoretical framework with which they can be explained. We acknowledge that our findings are not widely generalizable, but we argue that our selected case is a 'typical' case [41] that is representative of a large number of cases and is very likely to applicable to other similar environments – for example, wellness management in other countries.

Our findings and observations, taken together, suggest a need for a revised research and development agenda in this space. However, the exact nature of these developments remains open to further inquiry. We thus call for health technology reflecting the emerging policies of wellness management, preventative interventions, and decentralized/home healthcare. Specifically, this requires ICT that:

(i) Supports wellness management at an activity-level, rather than a user-level;

(ii) Supports the capture and communication of information in a way that heterogeneous actors can understand;

(iii) Supports the capture and communication of both physiological and social/psychosocial information.

Technology that can address these three challenges will go a long way to creating a more integrated and coordinated infrastructure that supports wellness management among the diverse actors involved. Such an environment would enable family carers, in particular, to add more value to the wellness management activity and may help to reduce their sense of isolation and frustration.

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Appendix – discussion guide used during semi-structured interviews and focus groups with carers

To what extent do you feel you can detect changes in [patient]'s wellness?

To what extent do you feel you can detect when new home care needs emerge for [patient]?

To what extent do you feel confident you know when a clinical health care intervention is necessary for [patient]?

To what extent do you feel confident you can remember all of [patient]'s care needs?

When discussing [patient] with a doctor, to what extent do you feel confident you can recall the details of what/when particular incidents occurred and what was done to address them?

When discussing [patient] with a doctor, to what extent do you feel you would be more/less able to discuss care requirements in you had a record of incidents and home care provided?

When handing care of [patient] over to someone else, to what extent do you feel confident you can remember and communicate all of the care requirements and preferences?

When someone else has been taking care of [patient], to what extent do you feel confident you know about any care provided and incidents that may have occurred?

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Highlights

- Illustrates the social and technological complexity of wellness management activities
- Shows lack of ‘access to’ and ‘sharing of’ wellness related information in such activities
- Demonstrates the need for development of new ICTs to better support family carers