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## Health and Social Care – Towards an Understanding of Wellness Management and the Role of IS

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### Abstract

Publicly provided healthcare systems are coming under increasing pressure worldwide because of aging populations, increased prevalence of chronic disease and spiralling healthcare costs. This pressure can be alleviated by focusing on community-based healthcare and empowering people to proactively manage their own general wellness. To this end, many employee wellness programmes have been launched, as have many technologies to measure specific aspects of wellness. However, wellness is a poorly understood concept and effective wellness-management is elusive and lacking in metrics. In light of this deficit, this research-in-progress draws on activity theory and attribute substitution theory to propose a preliminary model describing how wellness is managed by various actors (e.g. the individual, family carers, healthcare professionals) in the collaborative wellness management activity. The study's empirical data gathering reveals that wellness management is often inhibited because of an inability of these actors to access and reflect on the contextual factors that mediate the activity of managing wellness (i.e. the rules that guide them, the division of roles and responsibilities, and the tools that are utilised in managing wellness).

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*Keywords:* Wellness; Wellness Management; Activity Theory; Attribute Substitution; Family Carers; Care Co-ordination; Healthcare Systems.

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## 1. Introduction

Healthcare systems, worldwide, are overwhelmed by 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<sup>3</sup>. For example, within the EU, it is estimated that by 2030 there will be only two active people (aged between 15 and 65) to each person over 65. This will lead to an increased financial burden on countries and on their healthcare systems<sup>16</sup>.

Notwithstanding the increasing focus on patient empowerment and patient self-care in the case of people who are ill<sup>4</sup>, meeting the challenges of 21st century healthcare also calls for initiatives that keep people from entering the healthcare system in the first place. To this end, national prevention strategies<sup>24</sup> and employee wellness programmes<sup>5</sup> encourage specific healthy lifestyle choices in order to promote wellness.

Another trend in personal health and wellness management is the development of information and communication technologies (ICTs) that support self-regulation and behavioural change, and encourage people to engage in a healthier lifestyle<sup>18</sup>. Such initiatives are specifically designed and marketed to individuals with particular objectives. For example, wearable devices track physical activity in order to promote increased physical fitness<sup>9</sup>; sleep monitors help people to track and ideally improve their sleep<sup>21</sup>; and hypertension dashboards<sup>10</sup> are useful for people with hypertension.

Despite the fact that it has been proven that increased wellness leads to reduced cost of care<sup>22</sup>, to date, not enough attention has been paid to clarifying exactly what we mean by wellness or wellness management. Wellness is an ill-defined and poorly understood concept and little is known about how individuals may be empowered to assess and track their own general wellness in order to support decision making regarding the need for lifestyle changes or healthcare interventions.

In light of this deficit, this paper unpacks the activity of wellness management and explores the potential for information systems (IS) to support this activity. Section 2 discusses the notion of wellness management and highlights the potential for IS to underpin coordination and decision making in increasingly decentralised healthcare systems. Section 3 theorises how wellness is managed and proposes a preliminary model of wellness management. Section 4 outlines the research method and Section 5 describes preliminary findings from the study. Section 6 concludes by highlighting the contribution of the study and suggesting future research directions.

## 2. Wellness Management and the Potential Role of Information Systems

It is widely accepted both in academic circles and in the healthcare industry that health care systems are moving towards more decentralised wellness monitoring and management<sup>6</sup>. This gives rise to increasingly complex health care systems that include a multitude of heterogeneous collaborators, such as emergency clinical staff, hospital physicians and nurses, general practitioners, clinical specialists, pharmacists, community and home care workers, the patient themselves or indeed, family carers if they are unable to care for themselves. There are now more patients to care for, more actors to coordinate, and less funds available than ever before<sup>6</sup>. Vagueness around what is meant by ‘wellness’ and ‘wellness management’ is increasingly problematic because the ability to identify and communicate wellness is essential to coordinate activities that seek to manage/improve it.

The patient is increasingly recognised as the most crucial actor in this system<sup>15</sup>. Thus, their ability to understand and communicate their own wellness and their ability to make appropriate wellness decisions are vital. One of the key strengths of IS has been their capacity to enable the collection, processing and dissemination of information to support decision making<sup>1</sup>. It is logical therefore that IS could play a key role in individuals wellness-related decision-making. It has also been argued that the greatest impact of IS has become its ability to create linkages, not its ability to process internal data into information<sup>28</sup>. Thus, IS could support collaborative wellness management between various actors in the healthcare system, but this remains an under researched area. Further theorising in relation to this would help to illuminate how wellness is managed among various actors involved and improve our understanding of how IS can support this activity.

### 3. Theorising Wellness Management

This section theorises how wellness is managed by drawing on both activity theory and attribute substitution. Section 3.1 briefly describes activity theory and explains why this theory was selected as a primary lens for the study. The role of attribute substitution emerged during analysis, therefore, this theory acts as a secondary nested lens. Section 3.2 outlines this theory and explains its relevance to wellness management. Subsequently, Section 3.3 draws on these two theories to present a preliminary model for wellness management.

#### 3.1. Activity Theory as a lens

Activity theory (AT) has its origins in the Vygotskyian<sup>27</sup> concept of artefact-mediated and object-oriented action, whereby a human being's interactions with their environment are not direct, but are mediated by cultural tools (including IT). Engeström<sup>13</sup> expands on this interaction-oriented view of human activity to reflect the collective and collaborative nature of activity by incorporating two additional mediators: (1) the rules/norms that mediate the relationship between the individual and their community; and (2) the roles/responsibilities of actors that mediates their relationships with all actors involved in an activity (i.e. the community). Thus, while an activity is the basic unit of analysis, AT encompasses participating social actors, the technological and non-technological tools they employ, the rules and norms of the social or socio-technical context, as well as the roles and responsibilities of participating actors.

AT is particularly suitable to the challenges of managing wellness for four reasons. First, the context is included in the basic unit of analysis of AT<sup>13</sup>, which is particularly appropriate given the broad boundaries of wellness management (see Section 2). Second, AT adopts an interaction-oriented view of human activity to reflect the collective and collaborative nature of such activity. Again, this is useful given the collaborative nature of wellness management between clinical and non-clinical actors. Third, AT adopts a mediated approach involving information sharing between people in a system, rather than the individual information processing approach of many IS studies<sup>7</sup>. Fourth, AT emphasizes the importance of studying real-life use of technology as a part of unfolding human interaction in the world<sup>7</sup>, which is especially important for a domain in-flux such as wellness management.

#### 3.2. Attribute Substitution as a lens

The ability to make decisions and evaluate our environment depends on rational and reflective processes on one hand, as well as less-conscious and intuitive processes on the other<sup>8</sup>. The extent to which either type of process is relied upon in a given context depends on several factors. These include the familiarity of the task<sup>2</sup>, the speed with which the task must be performed<sup>14</sup>, and (arguably of most relevance to the topic of wellness) the perceived computational difficulty of the task<sup>23</sup>. This latter consideration appears at first glance to lend itself towards highly conscious and deliberate forms of cognition. However, exploration of decision-making and evaluation under conditions of high perceived computational difficulty reveals this is not the case, as less-conscious attribute substitution (AS) often takes the place of rational and reflective reasoning<sup>17</sup>.

AS describes a cognitive process by which an individual faced with a difficult problem may instead substitute a simpler heuristic attribute in its place. A commonly cited example of this describes a study by Stack *et al.*<sup>26</sup> in which students answered a two-question survey (i) 'how happy are you with your life in general?' (ii) 'how many dates did you have last month?' Results showed that there was little correlation when the general question was asked first, however the answers correlated at a level of over 0.6 when the order was reversed. This appears to occur because the general question is so challenging that those respondents will substitute the specific (and less challenging) answer to lower their cognitive burden. Kahneman and Frederick<sup>17</sup> used this study to demonstrate three key conditions for AS, namely: (i) the target attribute is relatively inaccessible; (ii) the substitute attribute is readily available; and (iii) reflection on the process of decision-making or evaluation is limited.

These three criteria are highly relevant to the issue of wellness management for two main reasons. Firstly, like happiness, wellness represents a broad and loosely bounded concept for many people<sup>25</sup>, hence its accessibility is low, substitutable alternatives are common, and reflection is challenging. This means that evaluations and decision-making around wellness management is prone to the same types of biases and heuristics documented above.

Secondly, there is heterogeneity among actors involved<sup>15</sup> and this means that available heuristic attributes may not be shared between individuals involved. For example, while one actor may substitute wellness for physical attributes such as pain, another may substitute it for social attributes, such as perceived isolation. This makes communication unreliable between actors and acts to inhibit early detection of needs, coordination of care, and evaluation of outcomes.

### 3.3. A preliminary model of wellness management

Drawing on Engeström<sup>13</sup>, this paper argues that the activity of wellness management between an individual patient (or family carer in the case where the patient is unable to manage their own wellness) and healthcare professionals in their healthcare system (either clinical or non-clinical), may be viewed as a *mediated activity*. The object of this activity is wellness management for the patient while the outcome is that patient's degree of wellness. The three key contextual factors that mediate the relationship between the patient, the healthcare professionals and their shared object are: (i) the allocation of roles/responsibilities between the patient and other healthcare professionals in the management of their wellness; (ii) the rules/processes/norms that affect the means by which their wellness is managed; and (iii) various technological/non-technological tools that are used in managing their wellness - see Figure 1 (a).

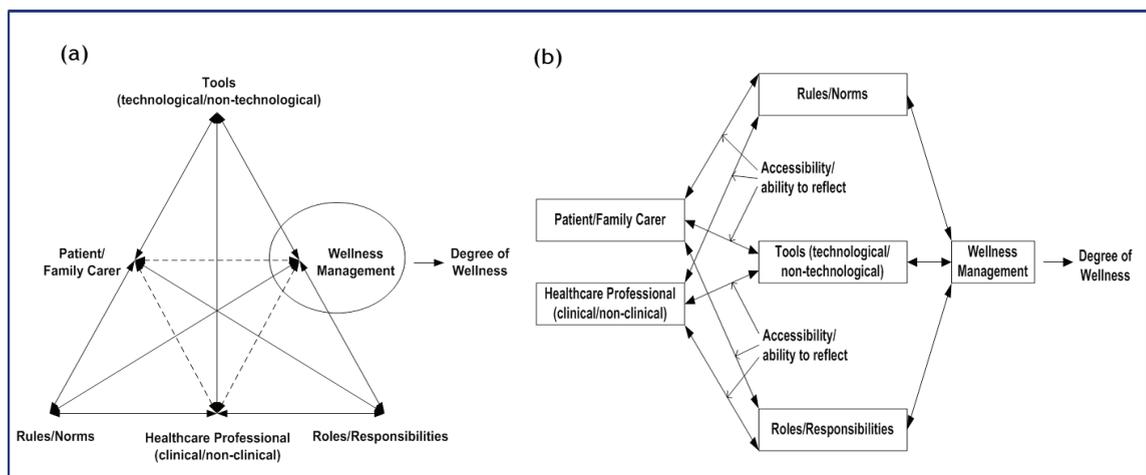


Fig. 1. (a) Preliminary model of wellness management activity system (adapted from Engeström 1987); (b) Redrawn to highlight mediating factors and illustrate impact of attribute substitution.

Furthermore, we argue that the effectiveness of each of these mediating contextual factors is impacted by the extent to which they suffer from AS - see Figure 1 (b). The roles/responsibilities, rules/processes/norms, and technological/non-technological tools involved in managing wellness are not shared unilaterally by actors, rather they intersect only under a subset of conditions. This means that some roles/responsibilities are hidden from patients and family carers – for example, diagnostic judgments based on specific tests and scans that provide important insights into the physical state of a patient. Other roles/responsibilities may be hidden from clinical professionals – for example, details of that patient's social interactions, which are considered an important contributor to wellness.

Thus, for all parties, at least some of these mediating factors are functionally inaccessible. This inaccessibility means that substitution is highly likely, a reality made more troublesome because actors are likely to have different backgrounds and degrees of clinical training. When inaccessible factors are substituted, they are likely to be substituted according to diverging heuristics. For example, while a clinical professional may substitute a patient's 'energy' for their ease of physical mobility, non-clinical actors or the patient themselves may substitute morale or their interest in leaving the house. 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.

#### 4. Method

The exploratory nature of the subject matter means that flexible and exploratory approaches to testing and refining theory are preferable to deductive and generalizable approaches<sup>19</sup>. Hence this study adopts a case-study approach, whereby one environment is explored in-depth in order to allow a wide range of potentially relevant and emerging factors to be observed<sup>20, 29</sup>.

The environment selected is that of family carers and clinical healthcare professionals in the Midwest and Southwest of Ireland. The embedded unit of analysis is the activity of managing the wellness of an individual patient. Informants in this region were chosen according to a strategy of theoretical sampling, rather than representative sampling<sup>12</sup>. Family carers were selected for the study as they are often required to collaborate with clinical professionals when the patients for whom they care are incapacitated or incapable of communication/decision making. This allowed our theorizing to capture additional social complexity of the wellness management activities in which they were involved, compared to patients managing their own wellness.

Data gathering was undertaken over an 11 month period January 2014 to November 2014. First, data was collected through 8 in-depth personal interviews with key informants (some participants were interviewed twice). Subsequently, a number of focus groups were conducted with experienced family carers and healthcare professionals. These were followed by a number of venting interviews<sup>11</sup> with purposefully selected long-term family carers and senior healthcare professionals (see Table 1). Interviews followed a semi-structured format. All interviews and focus groups were digitally recorded and memos were taken during and after data gathering.

Table 1. Data Gathering Conducted for the Study.

Technique	Description of Participants	No. Participants	Contact Time
Interview 1, 2	National expert long-term care, Executive US National Council on Aging	1	1.5
Interview 3	Senior officer, e-Health and Innovation, World Health Organisation	1	1
Interview 4, 5	Head of Innovation, Carer Organisation, Ireland	1	3
Interview 6	Senior manager, Care Association, Ireland	1	1
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
Interview 9	Experienced long term carer A	1	1
Interview 10	Experienced long term carer B	1	1
Interview 11	GP with interest in elder care and dementia care	1	1.5
Interview 12	Lead Geriatrician in two large hospitals, South of Ireland	1	1
		27	24.5 hrs.

#### 5. Findings

This section briefly describes the key findings of this case study. Section 5.1 highlights key insights in relation to how roles/responsibilities are managed between collaborating actors in the wellness management activity. Section 5.2 depicts key insights from the study in relation to rules/processes/norms and Section 5.3 outlines key insights with respect to technological and non-technological tools in this activity.

### *5.1. Attribute substitution in the management of roles/responsibilities*

Empirical evidence gathered in the case reveals several ways in which the management of roles/responsibilities may be inhibited by attribute substitution. Perhaps the starkest instance of this was observed when a mother caring for her terminally ill daughter described when the doctors wanted to tell her daughter about the terminal nature of her illness. Her mother 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 responsibility to inform the patient. The mother felt it was her emotional responsibility to protect her daughter from the truth, so that she could enjoy her remaining time. Neither party saw the full complexity of roles and responsibilities involved. Each had substituted a simpler heuristic version of those roles/responsibilities that prioritized the elements of care in which they were most involved.

From a family carer’s perspective, many felt that the significant amount of time they spend with patients means they are best positioned to assess when their condition has changed. This created some frustration when clinicians were reluctant to consult them in designing healthcare 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. She explained that when 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 it was a fear of having his medication changed or being told that he could no longer do certain things that allowed him to perform better when being evaluated. The family carer in this instance felt she had a role/responsibility in reporting important diagnostic information otherwise inaccessible to the doctor. Yet the lack of opportunity to reflect upon that information with the doctor meant that doctor was basing their diagnosis on substituted heuristics learned from other cases.

### *5.2. Attribute substitution in the management of rules/processes/norms*

Empirical findings also reveal several ways in which the management of rules/processes/norms may be inhibited by attribute substitution. A striking example involved in the provision of emergency care in non-clinical contexts. One family carer described how she had taken over from a hospice care worker when her husband was having a transient ischemic attack. 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 a norm and not of interest to the healthcare professionals involved, thus 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 according to a different set of norms. Had the healthcare professionals not observed these procedures serendipitously, it is possible they would not have become aware of the severity of the patient’s condition until he was under full-time clinical care.

A second example of attribute substitution in the management of rules/processes 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”. 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-based interventions were being made on the basis of both clinical rules (of which family carers had limited knowledge) and interpersonal rules (of which clinical professionals had limited knowledge). Thus both parties were assuming asymmetrically substituted versions of these activities, neither of which reflected their true complexity. Moreover, these heuristic-based understandings were not challenged because neither party was necessarily prompted to reflect upon them.

### 5.3. Attribute substitution in the management of technological/non-technological tools

The previous sections demonstrated that attribute substitution in the management of rules/processes/norms and roles/responsibilities mostly occurs because 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 revealed that actors apply attribute substitution because of a lack or complete absence of information altogether. The findings indicate that this absence of information primarily results from a lack of access to tools (e.g. IS) to help them track and manage wellness, a shortcoming lamented by several family carers. 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”. The inaccessibility of such information forces those family carers to assume some heuristic substitution-based estimate. This is made more problematic because the nature of such subtle deteriorations means there are rarely other sources of information against which estimates can be compared, making reflection a rarity.

A further issue 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. 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 carer’s inability to formally capture and relate the information necessary to demonstrate issues she had observed subjectively outside of clinical care (i.e. she knew that his condition had worsened compared to his normal condition). The doctor, who lacked this formal information about subtle changes in his patient’s demeanor, was forced to substitute heuristic-based judgements based on his own observations of the patient.

## 6. Contribution and Call for Research

This study illuminates serious shortcomings in existing wellness management practices. In particular, it suggests that wellness management is inhibited by an inability to gather and share key information about the activity in a way that is meaningful to both family carers and healthcare professionals. This study offers three key contributions to ongoing IS research and practice. First, the AT-based model of wellness management demonstrates the complexity of wellness management as an activity and the heterogeneity of the actors involved. In research terms, this perspective demonstrates the effectiveness of studying wellness management in a holistic and process-oriented manner, rather than focusing on compartmentalized elements of the care ecosystem. From a practice perspective, this suggests that developers should consider the role of multiple user types when designing products and services, as well as the existence of both explicit and assumed roles and norms.

Second, the AS perspective demonstrates that the activity of wellness management is inhibited by attribute substitution which in turn results from a lack of access to complete diagnostic and/or procedural information. This finding illuminates important flaws in existing wellness management approaches. Further, in design terms, this perspective offers a high-level strategy for improving wellness management. This would involve the identification and minimization of information asymmetry between different types of actors, as well as the introduction of formal processes that provoke reflection in situations where heuristics are applied.

Third, empirical findings suggest a distinct lack of IS support for wellness management as a health and social care activity. This lack of IS support is surprising, given the scale of the problem, the challenges of the activity, and the non-trivial issues currently inhibiting wellness management. Some technologies for physiological data gathering in non-clinical contexts are beginning to emerge as wearable technologies become more pervasive. However, little or no evidence was found to suggest these technologies have penetrated wellness management activities. This appears to be because the collaborative nature of the activity does not lend itself to piecemeal introduction of such technologies, and few (if any) seem to take an infrastructural approach. Further, despite widespread recognition that wellness involves physiological elements as well as social and psychosocial elements, no IS support is found which affords such ‘softer’ measures in the context of wellness management.

We, therefore, call for IS research and development that: (i) examines wellness management at an activity-level, rather than a user-level; (ii) supports the capturing and communication of information (currently not shared between actors in the wellness management activity) in a way that is intelligible for heterogeneous actors; and (iii) supports the capturing and communication of both physiological and social/psychosocial information between these actors.

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