Resident autonomy in assisted living facilities: A conceptual framework for transformative service research

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Abstract

In this paper we explore the concept of autonomy and its impact on health for older adults living with chronic illness. With the world's population growing older, along with increased incidence of disease, much needs to be done to mitigate the burden of illness for the health of the person, communities and the nation. Part of the solution of growing old with disease, is in the residential placement settings with service designed technology to aid the individual to maximize their quality of life. From a social ecological framework, we outline key concepts as reported by elders for designing transformative service. Determinants of autonomy both from a health and a design perspective were explored interprofessionally. The key concept as reported by elders for the meaning of autonomy was the ability to make their own decisions. The study concludes with prospective research plans to design a prototype solution to help mitigate autonomy.

KEYWORDS: autonomy, service design, assisted living, transformative service research

Introduction

In the United States, more than 835,200 older adults reside in assisted living and similar residential care communities (Center for Disease Control and Prevention [CDC], 2015). These communities provide services to individuals who often cannot live independently but do not require the degree of assistance that would necessitate residence in a skilled nursing facility (Khatutsky et al., 2016). Although the transition from residence in one's own home to residing in an assisted living facility is often necessary, most older adults prefer to age in place and avoid transitions (National Council on Aging, 2015). Moreover, the transition from independent living to a residential care community may threaten an individual's autonomy (Shippee, 2009). This is significant given that there is a growing body of research that suggests increased autonomy is associated with positive health outcomes and improved quality of life (Murphy, Cooney & Casey, 2014; Sikorska-Simmons & Wright, 2007). In the service design literature, scholars have argued that a greater sense of personal agency

positively impacts the perceived process quality of a service, thereby improving the person's functional outcome quality and capacity (Grönroos, 1984; Edvardsson 1997). There is an increasing number of aging adults living in assisted service (Harris-Kojetin, et al., 2013; Harris-Kojetin et al., 2016), yet little is known about their needs for maintaining their sense of agency or autonomy.

Assisted Living Facilities-definition and review

According to the National Center for Health Statistics (NCHS) there were in 2014 some 30,200 residential care communities, serving 835, 200 residents across the United States and these numbers continue to rise annually. These licensed, registered or certified residential care communities varied by bed capacity (Sengupta, Harris-Kojetic and Caffrey, 2014), and according to the skilled level of care provided (NCHS, 2016). The majority of residents live in communities with more than 50 bed capacity. Functionally, screening for cognitive impairment is done to determine dementia-specific programming or skilled level of healthcare needs (NHCS, 2012). Those facilities that provided assistive living services, when the resident required minimal care while living as independently as possible, with the availability of personal care aides (PCAs) made up approximately 94% of all these communities. These communities are found all over the United States and are growing as the aging population increases (US Census Bureau, 2014). The latter was the target population of our research.

A report from the U.S. National Center for Health Statistics (NCHS) released in 2016 entitled Long-Term Care Providers and Services Users in the United States: Data from the National Study of Long-Term Care Providers, 2013 – 2014 indicated that the daily use rates per 1,000 residents aged 65 and older in Massachusetts were 12.07 and was on par with the national estimates of 16.77 with a standard error [SE] of 0.42. When the rates were interpreted for those aged 85 years and older, that daily use rate rose to 44.21 with a SE of 2.05. According to the same NCHS report there are 13,600 licensed maximum capacity facilities for long term care in Massachusetts, USA, half of which are chain affiliated and 46.6% are Medicaid certified. With only 4,794 full time nursing and social work employees to serve 12,900 elderly living in residential care communities, the need to design services to maximize the autonomy of residents is crucial in helping to keep these residents as physical and cognitively healthy as possible. Today's innovative service designs though anticipated to be developed with individualized or unique features, will need to consider that adults ≥ 85 years old make up more than one half of the residents (59.1%), the majority are women 73.6%, most are Non-Hispanic whites and most require some help with activities of daily living particularly grooming. Most importantly, that it should be scalable at some point as the predicted growth rate of adults ≥65 years old, is anticipated to be 22.2% by 2020 and 25% by 2050; 83.7 million, almost double its estimated population of 43.1 million in 2012 (US Census Bureau, 2014).

 One cannot address the aging of Americans without attention to the health impact or disease burden to individuals, families, and society. Negotiating for health services and navigating the health system are integral aspects of managing care in the elderly, and thus autonomy is important. These episodes of transition care can be viewed as negative services. Negative services are those that are necessary but unwanted or perceived as stressful by the consumer (Morgan & Rao, 2006). Anderson and Ostrom (2015) identified several issues that may contribute to the conceptualization of a service as negative, including the chronic nature of a consumer's need for a particular service, power dynamics, prejudices, and marginalization (p. 244). The domain of autonomy has undergone paradigm shift, in the relevance to various disciplines, but one of its variable remain constant and that is the *desirability* of autonomy.

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Transformative Service Research

Transformative Service Research (TSR) is a burgeoning field in service marketing studies, yet much of the work in this realm is still conceptual, and more work needs to be done as quantitative and qualitative research. TSR is defined as "service research that canters on creating uplifting changes and improvements for the well-being of individuals (consumers and employees), families, social networks, communities, cities, nations, and ecosystems" (Anderson and Ostrom, 2015). It is research for the greater good, encompassing social responsibility, sustainability, health and economic growth, and is flourishing within the service and consumer research realms. Anderson and Ostrom (2015) defined transformative service research as "any research, regardless of academic discipline…that investigates the relationship between service and well-being," (p. 243).

The intersection of service design and health is not always with positive impact Subsequently, several authors (Morgan & Rao, 2006; Singh & Duque, 2012; Spanjol et al., 2015) have called for further research into negative services. The conceptualization of residential care as a negative service provides a framework for planning transformative service research that seeks to mitigate threats to autonomy in the residential care setting. In our study, we sought to learn elders' perspectives on their sense of autonomy for the purpose of designing a service system to make health related care arrangements among the population who needs assisted care. The purpose of this paper is therefore to provide evidence for understanding autonomy in the context of transformative service research. Using an interdisciplinary team approach, we synthesized findings from the design, marketing, and nursing literature to define autonomy, identify its determinants, and construct a conceptual framework of assisted living resident autonomy. We posited that qualitative research to support our hypothesis that service design for mitigating elders' autonomy in residential care communities required first-hand knowledge of this concept.

Autonomy

According to Spear and Kulbok (2004), autonomy "may be defined as a state of being independent or self-governing". Although the concept of autonomy was used in a variety of settings, it was not defined beyond the simple definition of independence or self-governance. Earlier studies examined it in relations to language development, (Littlewood, 1996). Spear and Kulbok (2004) raised three different areas as examples: nursing research on adolescent autonomy focused on self-determination, control, decision-making, and social and risk behaviours; education research examined autonomy in light of self-learning, intrinsic motivation, locus of control, and academic achievement; and psychosocial research focused on maturation, self-efficacy, independence, individuation, and self-actualization concepts. The authors identified several common attributes of the concept of autonomy including active, individualized, holistic, contextual, and developmental. What follows is a brief explanation of different perspectives of autonomy.

Determinants of autonomy: from a health perspective

Researchers in health sciences have identified several determinants of autonomy among older adults living in residential care. Primary among these determinants is the extent to which residents are presented with choices and maintain control over their decisions. As Rodgers and colleagues (2007) observed, residents who are involved in decision making, experience enhanced autonomy because the act of making a decision permits a continuation of the residents' prior social role. Specific examples of decisions that have been found to promote autonomy in the residential care setting included managing one's own medication rather than relying on staff (Perkins et al., 2012); deciding how much to eat or how much to stay awake (Tuominen, Leino-Kilpi & Suhonen, 2016); deciding when to go out and when to participate in communal activities (Bradshaw et al., 2012); and being able to access assistance 24 hours a day rather than following a caregiver's visitation schedule (Fjordside & Morville,

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2016; Tuominen, Leino-Kilpi, & Suhonen, 2016). As Bradshaw and colleagues (2012) observed, when daily life is regimented and restricted, a sense of institutionalized living occurs.

Relatedly, privacy has been identified as a second determinant of autonomy among older adults living in residential care. Bradshaw and colleagues (2012) found that having one's own living space—including one's own bedroom, bathroom, and storage—provided privacy and allowed residents to exercise control over their daily routines. Fjordside and Morville (2016) observed that while services provided by caregivers in the home permit care recipients to live longer in the community setting, these services often come at the expense of privacy. In addition, the authors observed that the presence of caregivers may be experienced by residents as a burden if the caregiver is unfamiliar with the resident's needs and preferences. For this reason, established relationships with long term caregivers promote resident autonomy. Likewise, maintenance of residents' existing relationships with family, friends, and neighbours promotes autonomy by continuing the social role held prior to the transition into the residential care setting (Perkins et al., 2012; Walker & Paliadelis, 2016). When examining brain health and the elders' social engagement, the ability to make independent decision was implied as being integral to well-being. (Meghan et al., 2017).

Determinants of autonomy: from a design perspective

Littlewood (1996) introduced two essential components of autonomy: ability and willingness. Ability depends on if an individual has both knowledge about the choices one has and the skills required to perform certain behaviours. Willingness depends on both individual's motivation and self-efficacy to perform a behaviour. Researchers in the field of Human/ Computer Interaction proposed four spheres of autonomy in technology design (Calvo, Peters, Johnson, & Rogers, 2014). First, designing autonomy within a software environment. Autonomy in this sphere provides freedom and control to an individual user while using a software or tool. Second, designing assistive technology to support and improve autonomy in daily activities. For example, using self-monitoring technologies to track physical activity and dietary choices. Third, using personalized design to address individual needs. Finally, designing technologies to improve autonomy through psychological development, such as raising awareness and consciousness and supporting self-reflection.

Batya Friedman (1996) discussed how designs can promote user autonomy. This author also raised an example of a new computer workstation to illustrate how hardware design can either hinder or help the user's ability to control the technology. Furthermore, by using the term of user autonomy, she referred to individuals who are self-determining, who are able to decide, plan, and act in ways that they believe will help them to achieve their goals and promote their values. Autonomy in this context is protected when users are given control over the right things at the right time and the challenge for design is to decide these *whats* and *whens*.

Davy (2015) explored the concept of autonomy within the context of inclusive design. She believed standard accounts of autonomy create inaccessible philosophical environments by focusing on individual capacity and naturalizing the exclusion of people with intellectual disability from the purview of political and moral theory. She also pointed out that sociopolitical understandings of autonomy as an individualized entity contribute to the lack of social and political assistance and resources offered to people with disability. She argued that a model of autonomy is needed that takes the vulnerable individual as its starting point and emphasized relations of support and advocacy, based on the premise that we all require supportive relationships and enabling environments in order to exercise autonomy.

Kim (2015) explored dignity and autonomy from three perspectives in her works on service design. This researcher believed autonomy is setting up self-governing rules, which is the beginning of the action, concluding that the three perspectives were self-control, self-

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decision, and free will. Kim believed that people find dignity when they act as autonomous agents of their own doing and being. From both the health and design perspective a framework of health that encompasses both was considered for use.

Conceptual framework

A framework that comprehensively examines the concept of living with chronic illness and takes into account the various domains was utilized as a resource for our study planning. As seen in the image below, designed by Robert Wood Johnson Foundation (RWJF) the delivery systems design is an integral part of any health system. Furthermore, decision making and the organization of health care is crucial to the implementation of any disease management or wellness program. The framework is presented below in Figure 1 RWJF Chronic Disease Management Model, as two major concentric ovals representing the constructs of Health Systems and Community. The relationship of organizations of healthcare, clinical information systems, delivery system design, and decision support all falls under health systems, which together is a subset of the community for an individual. However, the larger community also has self-management support and resources and policy that impacts a person health. The model widely used by governmental agencies in Australia, Canada and the US though useful in the initial iterative stage of our research was replaced with the Social Ecological Model to best explain the meaning of autonomy as reported by elders
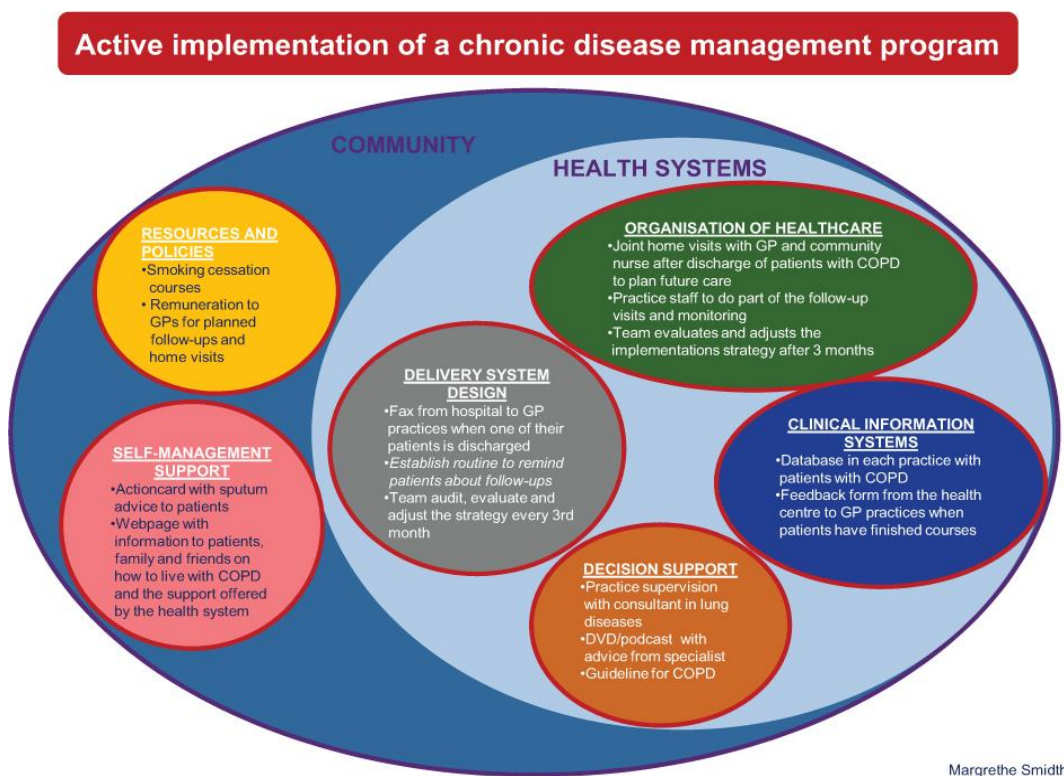

Figure 1. RWJF Chronic Disease Management Model

Autonomy conceptualized

The Social Ecological Model (SEM), is a framework for prevention, and provided the operational framework for this study. This framework shifts the current view of care from a purely medical model to that of a socioecological perspective. There are a few variations of

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the model, which was first developed as an ecological systems theory by Urie Bronfenbrenner in the 1970s. This was further developed by McElroy in 1988 to capture not only the physiological determinants of a human problem but also the behavioural and public health aspects of a problem or phenomenon under investigation (Coreil, 2009). According to Coreil (2009), these models are some of the most widely used for application to health promotion, the Center for Disease Control (CDC) also has used this model in health promotion and disease prevention efforts.

The SEM model has twenty-one domains which are divided into five hierarchical levels. Level 1 is Intrapersonal/ Individual. These are factors that impact the individual at a personal level for example; education, attitudes, genetics, and demographics. Level 2 is Interpersonal. This usually represents social networks and family characteristics or relationships in the immediate community that influence health care behaviours. Medical-provider health teaching and commonly prescribed treatment for disease can be included here. Level 3 is Organizational/ Institutional. These factors include social and cultural norms established by schools, workplaces, and neighbourhoods. It explores the health impact based on where people live, work or play. It also takes into consideration societal factors such as culture and religion (for example, people living in residential communities). Level 4 is Social/Policy: This could be public policy and regulation for example, the use of license and certification to determine who and where levels of care can be given to the elderly. It may also examine the effects from the built environment, socioeconomic, public facilities and health care needs. Level 5 of the SEM is most distal to the individual and is the level at which the individual has the least control over, it deals with the societal environment, such as the health facilities, economics, educational institutions, policies, and other largescale infrastructure of society (Coreil, 2010) including health insurance.

A model of this type is fitting when studying a condition as complex as elder care and designing for autonomy. The status of autonomy can be affected by having physiologic problems, or mental incapacity (inability to make decisions on their own). There may also be health literacy concerns in which the subject lacks the knowledge or understanding of navigating the system to protect their well-being. The community changes with the varied human and economic resources availability. Even standards of care or policies that leave varied levels of uncertainty among family and health practitioners for screening and treating frail adults can contribute to the complexity of aging in America phenomenon. The levels for this framework are illustrated in Figure 2 (Conceptualizing Autonomy using the Socioecological Model (SEM) below to show its construct alignment to autonomy and sets the groundwork for user engagement service designing.
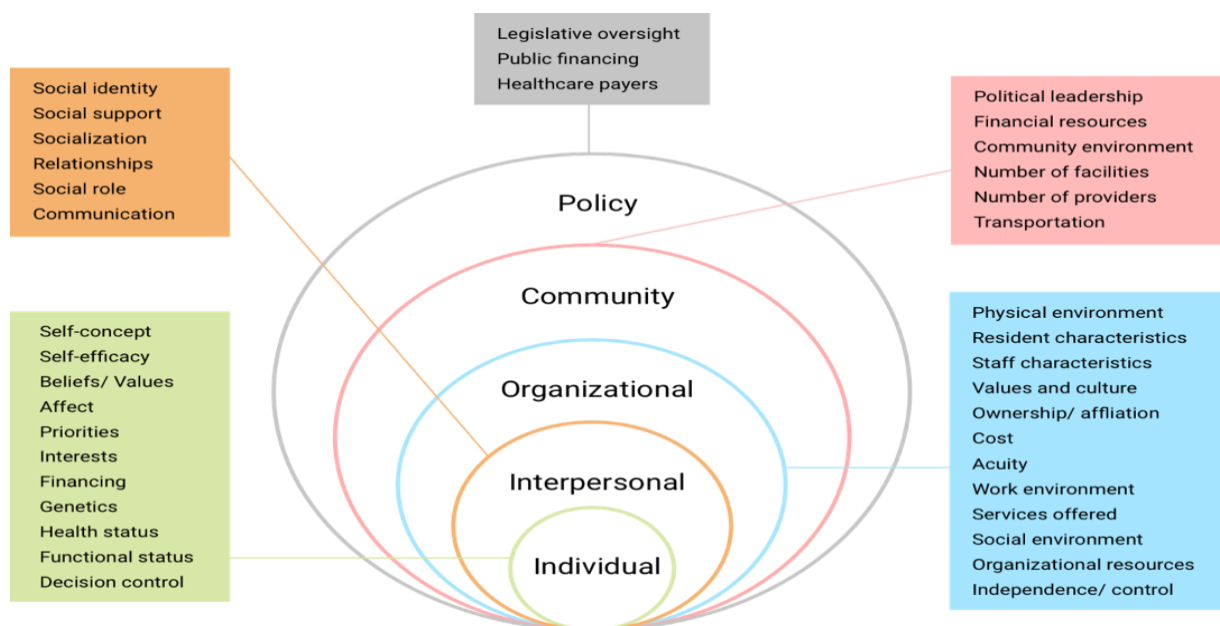
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Figure 2. Conceptualizing Autonomy using the Socioecological Model (SEM)

Methodology

Our research was an iterative process that started with the literature review to determine gaps in elderly healthcare and scope of the problem. Then with institutional review board (IRB) approval we conducted our study which included face to face recorded interviews, participant journaling and in- home observation of those person who met the inclusion criteria. If they met the inclusion criteria of being 65 or older, was fluent in English and had one or more chronic disease and resided in a residential care community they were invited to participate.

People then self-selected to be part of the study and underwent two screens, (1) was to determine cognitive ability using the Allen Cognitive Level Screen [(ACLS) leather lacing] tool and were excluded from the study if their scores fell below 5, n=1. The ACLS tool was developed according to Allen, (1991) to grossly estimate a person's higher functioning cognitive processing capacities, learning potential, and performance and problem-solving abilities. The use of this tool was meant to screen out any of the adults who had mental impairment or dementia at the level that impaired functioning or engaging with our research team. The ACLS tool is an evidenced based standardize screening assessment. (2) Was to evaluate their literacy in medicine using the 'Rapid Estimate of Adult Literacy in Medicine' short form (REALM-SF) tool. According to the Agency for Healthcare Research and Quality; Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. The tool has been validated and field tested in a variety of setting, (Arozullah, 2007). The research team felt these two pieces of information were also important to know as we ideate and propose the service design prototype. The participants were given a small monetary incentive for their participation.

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Results

In the first phase of the study, participants [n=10] were interviewed, they ranged from 65 to 90 years-old, were female and predominantly Caucasian. They had one or more chronic disease with varying obvious levels of physical impairment, and all communicated in English. Although they came from many States across the USA, they were now living in a single residential care community designed for seniors. Their living in the residential community ranged from a few weeks to 21 years. From the 2-week journaling activity, there were 135 journal entries received fully completed from n=9 participants. In home observations were done with n=9 participants. The next phase informed by the findings from the interviews, journaling and observation was a combination of ideation, territory mapping and then story telling. Armed with these stories, solution and proposed outcomes, we conducted four focus group with participant and key informants n= 24 two of these groups included participants from the first phase of the study.

Using Dedoose Web 2.0 for data analysis and thematic formations we found that participants described autonomy in a variety of ways consistent with the science of autonomy, but the most common themes were (a) making one's own decision; (b) completing one's own task (errands, financial management) and (c) having the means (financial, transportation and mental or physical health) to achieve one's goals. In the Figure 3 below, Autonomy defined by elders, excerpts from the interview demonstrates this significance:

Participants' definition of *autonomy*

1 Making one's own decisions	2 Completing one's own tasks	3 Having the means and ability to achieve one's goals.
Interview 3XX *"Taking care of myself, nobody telling me what to do or when to do it, driving my car, handling my own finances, being physically able to do what I need to do. ...the main thing is nobody telling me what to do or when to do it"*	**Interview 3XX** *" I think as you get older, you have to cooperate. If someone tells you take your..... You have to do it. But I'll probably only do something kicking and screaming. But no, you really. I used to tell people, if you take a little help, you can stay independent longer."*	**Interview 3XX** *"Especially the day you have to give up your license. You might as well just give up. You know because really you're losing your independence when you do that."*

Figure 3 Autonomy defined by elders

Relationship with children ranked at the top of their list. For many of the participants, their children were the impetus for them moving into residential care; participants described moving to live closer to their children, and primarily described the relationships with their children as supportive. Participants received assistance with groceries, medications, and other errands from their children. Children also provided social contact and often took participants out for dinner or other social activities. Participants did, at times, describe relinquishing autonomy (e.g. moving out of their own home, giving up their car) at the request of their children. Participants also lamented that they [did not accept well the shift in role responsibilities] were not needed by their children in the way they were previously. The top code co-occurrence for autonomy was as illustrated in Figure 4 below. Decision making and control was reported together; transitions were paired with loss, children, family and friends;

self-management was paired with medication; transportation was paired with friends and children and volunteering was paired with community
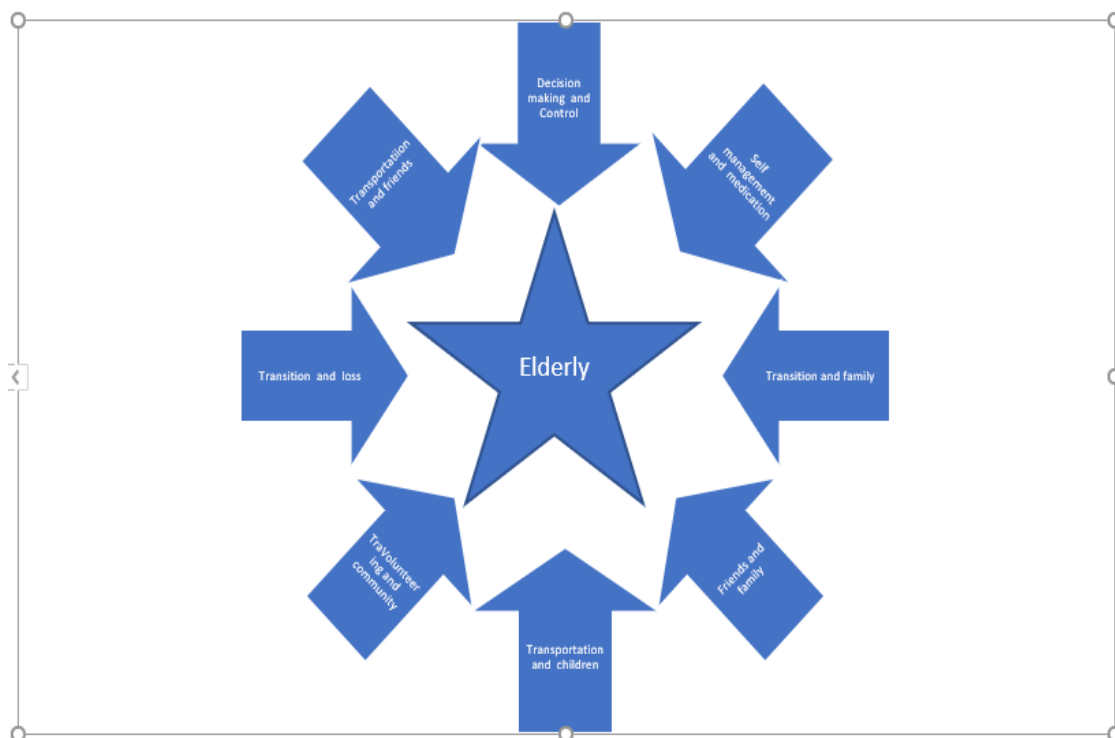

Figure 4 Top code co-occurence

The decision making was not always of what to do, but the sacrifice made, according to participant speaking in relevance to transportation, "I try to limit that to the important places, like church or going to …I went yesterday to visit a friend of mine over in a home, a group home, excuse me over in (town), I went over and visited her yesterday. I forego church, because it would cost $7 or something to go to church, and [additional] $10 to [town], so I just couldn't go." Another lamented about transition and loss, "I had a really wonderful dog and I could not bring him. I dropped the lab dog anyway. When I moved, ... I had him for 10 years. I never intended to ever … give him up, …my daughter insisted that I needed to do that." The journaling prompted by three open ended questions yielded similar results as that seen in the home. The in-home observations indicated that the majority of help were required for arranging social activities, shopping, medication use, exercising and bathing.

Discussion

In the voice of the elders the interpretation is that future generations play a key role in what happens to the elderly, and service design will have to capitalize on this vital link. One must consider that the relationship of children to elderly is crucial to the health and well-being of the seniors. This was a homogenous group and with the exception of age and well-being status, the latter attributes were not measure but implied from our visual observations and participant conversations, the group lacked diversity. There were no men in the participant group although men lived in the residence. This was not uncommon a finding as more women than men tend to engage in qualitative research and furthermore, women live longer than men and may find the benefits of improving self-care more appealing. Through this triangulated measure of autonomy, the research team felt there is enough support of the

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hypothesis and evidence to move to the next phase of designing a prototype. The design ideas will be iterated and tested by diverse models used in a service design approach, such as territory map, stakeholder map, perception model, market analysis, customer journey, product-service system model, etcetera. The final prototype will be an experience scenario and a service blueprint as a pilot for a working service system that can be validated in future research.

Conclusion

The focus of care for elders is transitioning between care environments and maintaining the elderly's autonomy wherever possible is most beneficial. This is economically beneficial for the patients, and also improves the quality of service from care providers (Mynatt and Rogers, 2000; Hellström and Hallberg, 2001; Navaie-Waliser, et al., 2004). This change aligns with the recent "sharing economy" that provides better sense of agency to individuals by decentralizing the locus of care from a central organization to service co-producers at the nodes of the network (Lessig, 2008; Kim, 2015). Clients who live alone with pre-existing medical illness pose a challenge in the management and coordination of care. More critical is the client whose first entry into the health system is secondary to a critical illness event. Safety calls, wellness calls, arrangement of social services, accessing their residence, and mobilization of medical specialty takes on significant relevance for the patient who may lose their sense of independence rather quickly. When the elderly can continue to manage their care with the help of well-designed services and can orchestrate that input into decision making, health outcomes are reportedly better.

At the center of the service system, patients and caregivers are empowered to personalize their options and pathways by co-designing healthcare service with the help of information technology. In order to develop the digital and human capability of the service system, a human-centered service design approach is recommended and planning should engage a variety of stakeholders including elders and their children to determine prototype usability and feasibility. The growing population of aging adults who live alone raises health, safety, cost and resource concerns for the local governments and health care organizations. Our findings on the meaning of, and conceptual framing of autonomy in elders is consistent with findings in the literature. Our research contributes to the resolution of the emerging social problem of dependency among elders living in residential settings. It offers theoretical and practical implications for designing service, as well as serving as a case study of the growing field of patient-centered multidisciplinary research.

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