Transforming the 'Home from Hospital' Experience by Engaging Volunteers

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Introduction

People being discharged from hospital, particularly older adults, face challenges as they attempt to adjust and cope during the first couple of months at home. Krumholz has identified 'post-hospital syndrome' as an acquired, transient period of vulnerability - due to impaired physiological systems and depleted reserves which limits an individual's ability to adjust and manage health issues post-discharge. Various types of personal health, practical and social supports are needed in order for individuals to re-integrate into the community and transition home, and well facilitated and supported community reintegration can decrease adverse events and re-hospitalization (Gwadry et al. 2004; Kwan and Sandercock 2002; Teasell et al. 2003). There has been increasing attention to models of transitional care and services, including discharge support services (Chiu and Newcomer 2007; Mistiaen et al. 2007) and patient navigation. Transitional care may include a broad range of services and environments that assist patients with safe and timely passage across care settings and between different levels of health care (Naylor and Keating 2008). Patient navigators help guide patients through the health care system. A systematic review conducted by Manderson et al. (2012) on the role of navigators in helping chronically ill older adults through healthcare transitions (e.g. hospital to home), eleven navigation roles were identified. Navigators can assist with: discharge planning, care planning, coordination of care, phone support, and home visits. They can also act as liaisons with medical and community services, offer patient and caregiver education, purchase services with a provided budget, and help patients feel empowered.

Research on the delivery of such care has predominantly been focused on the role of allied health professionals, nurses and other healthcare professionals, with limited attention to the engagement of the informal healthcare sector, specifically volunteers. Some of the existing evidence, particularly in the area of cancer care, finds that volunteers can play an important role in supporting care transitions. Lorhan et al. (2015) found that volunteer patient navigators enhanced patient experience noting: "the primary functions of peer/volunteer navigation include guiding people through the healthcare system, assisting with emotional, administrative, informational and practical support, and addressing barriers to accessing care." Currently, however, very little is empirically known about the specific roles they undertake, the kinds of services they deliver, and how the capacity for volunteers to support patient care transition is developed, despite there being several grassroots initiatives.

This paper synthesizes evidence from 4 case studies of volunteer provided transitions support services for older people post discharge from hospital. The purpose of this paper is to identify the central/core elements of these programs, the facilitators and barriers to service implementation, and the perspectives of providers and recipients regarding these services.

Study Approach

A comparative case study design was utilized. Case studies allow for the integration of multiple, diverse data to provide a deep understanding of each case (Stake, 2008). A comparative case study design allows for the analysis of two or more cases, examining similarities and differences across sites, in order to assess how or why particular programs or policies work, or fail to work (Goodrick, 2014). Through an environmental scan and referral sampling, we identified volunteer provided transitions support programs that met the following criteria:

- Programs and services were delivered by community based organizations, with volunteers as the primary service provider
- Program services were focused on return to independent living post hospitalization
- Programs were focused on adults
- Program was an established model of service, not a pilot or demonstration project

Programs explored in England included: Age UK Herefordshire & Worcestershire Home from Hospital; and Royal Voluntary Service Leicestershire Rutland Home to/from Hospital. Programs explored in Canada included: British Columbia Stroke Recovery Association Community Navigation Program in Nanaimo; and March of Dimes Peers Fostering Hope in Toronto. Details regarding each case can be found in Table 1.

<u>Data Collection</u>

A multi-method data collection strategy was employed, comprised of interviews, focus groups and document reviews. Data was collected regarding:

- Program Purpose
- Services provided
- Service administration and demographics (e.g. funding, staffing, volunteer numbers, recruitment and training)
- Service delivery processes
- Evaluation process and outcomes
- Perspectives on the program or service by administration, volunteers, clients regarding value, as well as successes and challenges experienced

Semi-structured interviews with volunteers, patients, caregiver/families and volunteer resources/directors of each program provided a rich description of each program. Interviews and focus groups were conducted with a total of 54 participants (15 program staff, 22 volunteers, 17 service users).

Program documents were also collected, retrieving both public information regarding the programs, and administrative documents provided by program staff. Documents included information about programs on websites, forms used for recruiting volunteers, training manuals, volunteers' job descriptions, intake assessments, discharge and signposting forms, as well as program evaluation documents, and any program reports.

<u>Data Analysis</u>

Throughout the data collection phase we transcribed interviews, created case summaries and wrote analytical memos. Data collected through semi-structured interviews were analyzed thematically through an inductive approach, identifying, analyzing and reporting patterns (themes) within data (Braun & Clarke, 2006: 79). Since we employed an inductive approach, codes and categories used for analyses were derived directly from the interview data (Hsieh & Shannon, 2005). As a result, we were able to generate a rich and detailed account of the cases (Braun & Clarke, 2006). Common threads were searched for and identified across the entire set of interviews (DeSantis & Noel Ugarriza, 2000). The documents were analyzed through an iterative process of skimming (superficial examination), reading (thorough examination), and

interpretation (Bowen, 2009). Elements of content analyses were used, where a first-pass document review was conducted and meaningful and relevant passages were identified (Bowen, 2009).

Study Results

Selected Cases

The programs had similar missions and objectives, with support and services provided at different points in the transition between hospital and home. Some programs were initiated during the individual's hospital stay, while others were solely community based. The programs were designed to help service users transition home after hospitalization, promote independent living, reduce social isolation, and signpost to other sources of support at different points of the transition. The programs recognized the value of utilizing volunteers. All programs purposely recruited volunteers using formalized human resource processes used to guide the intake mechanisms (recruitment, screening, interviewing), training, and performance assessments. The number of volunteers per program varied, with the smallest program having 16 volunteers and the largest program having 67.

Evaluation mechanisms varied between the programs. Two programs had more fulsome evaluations (process and outcomes) due to funding requirements. The others captured process data (number of referrals, contact hours). All programs captured service user satisfaction data.

Perspectives of Providers and Recipients

i.   Programs provide a safety net for service users

Many service users stated that they would rather not rely solely on friends and family support as they transitioned from hospital to home, and that they were more comfortable asking volunteers within a formal service for help. We asked a service user how she would cope if she did not have a volunteer and what she thought her recovery would look like, and she replied:

> *"I dread to think I would just have been reliant on friends, and you'd just get more and more embarrassed about what they were doing for you because you can't keep asking. I mean 6 weeks is a long time to have someone that you've got to keep saying, "Can you do this? Can you do…"*

Moreover, a sense of trust and comfort was demonstrated by the service users, knowing, "I just knew that they would send you someone that you could trust." This provided further comfort to families and caregivers of service users, who also experienced a sense of relief. A service user discussed how her daughter felt more at ease knowing that she had help:

> *"Oh yes, it's taken a lot off her mind knowing that I am being looked after somewhere along the line. If it's not the district nurses and the physic, I've got AgeUK people. You know, somebody coming in to look after the sanitary sort of things. So it's taken a lot off her mind. She's got enough problems of her own."*

In addition, service users of programs located in Age UK Herefordshire & Worcestershire and the Royal Voluntary Service of Leicestershire Rutland also underwent various risk assessments,

including health and wellbeing assessments and home and environment/safety checks. Table 1 provides a summary of the risks and conditions assessed by the home from hospital services.

Table 1: Assessment of risks and conditions

Age UK Herefordshire & Worcestershire (Home from Hospital)	Royal Voluntary Service of Leicestershire Rutland (Home from Hospital)
-Assessment checklist includes considerations of health (emotional and physical), environment (situation and condition), resources (financial, home, care and travel), background and social relations (family/neighbours/friends supporting-separation and bereavement) -Health and Safety check sheet includes assessment of outside property, inside property, and other.	- Assessment checklist includes considerations of health and wellbeing; emotional health; social connectedness; practical support - Referral forms (RVS) and first contact checklists also assess health and wellbeing and safe and security; consider/assess staying well at home, feeling safe at home, managing money well, and staying active, social and healthy.

ii.   Programs provide psychosocial support

Many volunteers noted that service users often express a feeling of loneliness and are sometimes anxious about returning from the hospital to face of various sources of uncertainty. Some service users lack social support while their friends and family are living away or are otherwise unavailable. Volunteers often noted that befriending seemed to be one of the most valuable services of the programs. Many program coordinators mentioned how some service users need a befriender to encourage confidence to physically move and engage in various instrumental activities of daily living. Thus, overall, we found that programs appear to provide psychosocial support.

Participants from March of Dimes Peers Fostering Hope program in Canada discussed how the idea of 'hope' is important for patients who are vulnerable and do not know how to transition home and navigate in the community. Since Peers Fostering Hope volunteers are also individuals who have had a stroke, they are able to provide psychosocial support through sharing their experience with having a stroke and be part of the patient's journey.

> *"So really a part of what this program is about is sending a message of hope. It's a simple as that. That is the foundation of this program. And it's going to become the foundation even when we're talking about how it's going to happen in the community because it's going to be that message of hope. That eventually, we think, will then lead this person who's isolated in their home possibly even to get into their community more. Right? So it is about transition. Because if you don't have…if you don't start somewhere, where do you go next?" (Coordinator, PFH, MOD Toronto).*

Participants noted that peer volunteers can sometimes provide a lasting psychosocial impact on service users: "*One participant said that one visit from that peer volunteer had more impact than*

the last 6 weeks of rehab because that person gave that hope and inspiration and motivation and that drive. You know, that's incredible valuable work."

Another coordinator that managed peer volunteers explained the importance of psychosocial support for the patients:

> *"We can do physical rehab on anybody. That doesn't mean they're going to adjust and do well. They might walk but that doesn't mean they're doing well. Right? So to me, you have to have that psychosocial piece"*

iii. 'Bridging the gap'

In England, where there is an emphasis on health and social care integration within the health system, the programs examined in this study appear to fill a gap in social care. There is recognition of the fragmentation of care, and the gap between hospital and home/community. We found that the transition programs augment social services. Volunteers discussed how, since care is fragmented, they are there to ensure that support is re-established when individuals return home. In that sense, they view themselves as carers:

> *"This particular client had just been discharged from hospital. So she's still a bit confused. So I just had to make a few phone calls to make sure that she had the support re-established. And I think our role basically essentially is in that aspect. That, you know, we're carers at the moment. There's lots of different aspects. And it's all been fragmented. But I'm forever sort of trying to liaison on their behalf to GPs and nurses […]"*

Community reintegration is often viewed as important by the program coordinators for patients transitioning from the hospital to home. Program staff discussed the need to understand what kinds of social support are available in the community, and ensure that stroke patients are connected with services that they need. A program coordinator noted that peer visitors and community navigators can facilitate the connection:

> *"Making contact with someone from community into hospital as soon as possible yields great results in terms of community reintegration. So the peer visitation piece about having that connection, that friendly face. And what we've done is that we've developed a form that people, where possible, get referred to a visitation, a peer visitation, and the navigator."*

iv. Potential for improved outcomes

Many coordinators of the programs believe that hospital readmissions could be reduced as patient outcomes are improved. Program coordinators consider how the supportive tasks volunteers perform, for example – providing transportation to medical appointments, could potentially reduce hospital admissions by increase access to primary care. At the same time, how these client and system outcomes are reported is particularly important to secure funding from health authorities and other sources. A coordinator noted:

> *"Obviously reducing social isolation has an impact on readmission to hospital. But so also does picking up on dropped medical appointments and things that have got interfered with by admission to hospital potentially. And risk of falling, these are things*

that we look at and follow up. Because it's increasingly a statistic which…It's what was instrumental in getting the city funding from the clinical commissioning group. It's really important that we measure it, that we ask it. That we're as accurate as possible in finding out what readmissions there have been, and recording them and being able to give an accurate figure on it, and being able to reduce it whatever way we can." (RVSLR).

Discussion

The findings of the study highlight the contributions which volunteers and the voluntary sector can bring in bridging the gap in transition between hospital and home and/or community. The programs explored in this study illustrate how the voluntary sector can serve to help integrate health and social care, and reduce problems of social isolation. As health systems throughout the world are tackling issues of social isolation, and are re-structuring healthcare delivery to improve health and social care integration (WHO), the voluntary sector may become an invaluable partner that can provide services in health systems that are becoming increasingly resource constrained. Overall, as the findings suggest, the programs can provide a 'safety net' for patients and promote independent living. Volunteers also provide unique contributions in social care. Volunteers may help individuals regain confidence as part of rehabilitation, provide psychosocial support, or provide residual support in intermediate care (Department of Health, 2001a, p.10). Having skilled volunteers that are adaptable, flexible, and have good interpersonal skills can have a positive impact on older adults' experiences returning home. While the findings suggest that the voluntary sector can improve patient recovery and overall patient experience transitioning home, findings of the study also suggest that it is imperative that volunteers must be vetted and provided with training and support. Moreover, clearly defined roles for volunteers are needed, where activities and role boundaries are delineated carefully. Literature on volunteerism indicates that to foster volunteer retention and consistency, volunteers must be given meaningful roles (Schnell & Hoof, 2012). As the findings demonstrate, the volunteers working within the programs explored identify themselves as providing meaningful care in the transition experience of patients.

There has been increasing interest in leveraging volunteers to provide various forms of support with health services, particularly supporting patients transitioning between acute, primary and social care. 'Intermediate care' is seen as a bridging function between hospital and home (Andrews, Manthorpe and Watson, 2003) and is aimed *'toward promoting faster recovery from illness, preventing unnecessary acute hospital admissions, supporting timely hospital discharge and, most of all, enabling people to retain their independence for as long as possible'* (Pearson, 2002: 32). Increasingly, intermediate care is described as "*That range of services designed to facilitate the transition from hospital to home, and from medical dependence to functional independence, where the objectives of care are not primarily medical, the patient's discharge destination is anticipated, and a clinical outcome of recovery (or restoration of health) is desired*" (Steiner, 1997:18). Some literature exists surrounding volunteers in intermediate care, however it is still limited. Thompson and Wilson (2001) note that for people with existing skills or experience in healthcare, volunteering in transition support services may make use of what these individuals can offer, and make this type of volunteering particularly meaningful. Transition support services are a structured service and can offer structured voluntary work, and some volunteers may find this attractive, especially for those moving in and out of employment (Bradley, 2000). Thus, there are mutual benefits for volunteers and beneficiaries of care.

However, while there are noted mutual benefits for volunteers and beneficiaries of care, very little research is available on how intermediate care, supported by volunteers, has benefited patients.

Patients with complex needs being discharged from the hospital are often vulnerable and in need of services that address both health and social issues. For example, patients with multiple chronic conditions and complex therapeutic regimes typically receive care from many providers and move often within healthcare settings. This group of patients have complex healthcare needs; however, the care received is often incomplete, inefficient, fragmented, and sometimes ineffective (Nelson, 2016). The heterogeneity of people with multiple intersecting needs in terms of illness severity, symptomology, functional status, prognosis, and personal priorities makes discharge planning and post-discharge care challenging. Health and social issues can further complicate the transition process and adversely affect physical recovery, mood, participation and social balance, quality of life and ultimately, self-management and self-care capacity of patients and caregivers. These issues and others may impede early engagement with services and potentially lead to exclusion from effective and appropriate self-management, which can create significant burden for adult patients and families, and ultimately the health care system as reflected in potentially preventable readmissions. Therefore, as complex patients move within healthcare settings, high-quality care that addresses both health and social issues is important.

As people with complex needs deal with a range of health and social care issues, they are particularly more vulnerable to experiencing the problem of social isolation. They may also have a more challenging time with navigating the community to obtain appropriate services and re-integrate into the community. The voluntary sector can play a unique role in helping vulnerable populations to identify and provide various kinds of supports and services, such as those provided by the programs explored in the study. In order to leverage existing community and voluntary sector infrastructure to develop transition programs that are volunteer-supported and adaptable to the needs of service users and community, we believe it is necessary for programs providing community reintegration support to be developed collaboratively between health, social and voluntary sectors. As people often need support at the hospital (before discharge) and before returning home, hospitals must work with community and voluntary organizations to ensure that supports are available before patients return home. More importantly, the findings also demonstrate how support must be continued after people return home. Services that provide practical support and help with community re-integration and reduce social isolation can have a profound impact on the transition experience, and potentially save healthcare resources as hospital readmission rates are reduced.

This paper recognizes the value of volunteers in providing elements of transition support and in playing an essential role in improving patient experiences. Literature on volunteerism in health services note that volunteers could contribute to health system efficiency and help to improve health outcomes (Handy and Srinivasan 2004). However, for such benefits to be realized, some have argued that volunteers need be considered first as a 'health human resource' (Nelson, Yi, Schwebel, 2016). While there are a number of barriers to engaging volunteers in patient care, for example those that relate to risk, liability and confidentiality concerns, in some environments, volunteers are considered an essential member of the health team and are engaged in direct patient facing care. In resource-constrained environments, volunteers are more depended heavily upon in order to provide essential care and services (Bangdiwala, Fonn, Okoye, & Tollman,

2010), thus encouraging health systems to mediate barriers relating to risk, liability and confidentiality.

Conclusion
Volunteer supported patient transition programs offer a range of practical and social supports that improve patient experience and outcomes, and also provide cost savings to health care systems. As health systems become increasingly resource constrained, it is imperative that the utility of hospital to home programs and their impact on outcomes and experience of people and their families must be evaluated rigorously, and further assessed for transferability and generalizability. Furthermore, future research should examine the impact of such programs on caregivers and how to better integrate caregivers as beneficiaries of transition programs.

Case Name	Home from Hospital - AgeUK Herefordshire & Worcestershire, England	Home from Hospital – Royal Voluntary Service Leicestershire Rutland, England	March of Dimes Peers Fostering Hope – Toronto, Ontario (Canada)	British Columbia Stroke Recovery Association Community Navigation Program – Nanaimo, British Columbia (Canada)
Program Purpose	This program provides trained volunteers to help older people, aged 55 and over, transition from the hospital to home.	The program provides older people home from hospital services for a period of up to six weeks	Provides trained volunteers, who have experienced stroke or are caregivers, the opportunity to meet with people in hospitals who have recently experienced a stroke and their caregivers or family.	The Community Stroke Recovery Navigator program was a pilot program that provided support to stroke survivors and family caregivers through the transition from hospital to home and community.
Program Clientele and Admission Criteria	Over age 55, resident of Worcestershire, live alone and be unable to live independently in the short term	Service users are usually 75 years of age and over, live alone, or is a carer or in a co-caring relationship, and have limited or no social support locally and no social care package.		Individuals referred to the program needed to have a confirmed diagnosis of stroke (ischemic or hemorrhagic), had to be living in the community prior to having a stroke; had a caregiver available and interested, and be a resident in the pilot communities
Funding Source	The service was funded by Worcestershire County Council.		The program is delivered in partnership with March of Dimes Canada and Toronto Stroke Networks. It supported by the Dr. Ed & Bobby Yielding Fund for Stroke Recovery	The program was a partnership of the local health authority, local hospitals, community organizations and the Stroke Recovery Association of British Columbia.
Services Provided	Referral Process. 6-week service provided free of charge. Needs assessment conducted once service user is at home. Support includes: shopping, light housework, collecting prescriptions, support to attend healthcare appointments, emotional support, and signposting to other services. Personal care is not provided.	Referral Process. 6-week service provided free of charge. Program is initiated prior to hospital discharge with assessment of need. Assistance with meal making, dog walking, gardening, shopping, collecting prescriptions, transportation to appointments, seated exercises, and befriending.	Individualized support to people with stroke and their family and/or caregivers is provided through hospital peer visits and community support groups.	The program had several elements. They included: i) linking stroke survivors and caregivers with community resources through a brokerage management model with co-created service and goals plans; ii) help service users and caregivers navigate community services; iii) monitor the implementation of service user service and goal plans; iv) create a community directory; v) build partnerships amongst providers and community service organizations; and vi) provide stroke recovery education to stroke survivors and caregivers

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