Abstract

Aims. 1) to generate in-depth insights into how nurses are working with older people with multiple long term conditions; 2) to gain an understanding of how nurses perceive professional patient navigation; and 3) to explore the barriers and facilitators to nurses adopting a navigation role in the context of Primary Health Care practice.

Background. Internationally, Primary Health Care has been identified as the main navigation point for older people with multiple long term conditions. Navigation models have been developed in cancer care but there is a lack of research in the context of Primary Care. There is also little evidence regarding the extent to which current work patterns of nurses providing care for this patient group fit with professional patient navigation models.

Design. A descriptive exploratory qualitative study.

Methods. Semi-structured audio recorded telephone interviews were conducted in 2012 with nurses in New Zealand who were working with older people with multiple long term conditions (n=42). Interviews were transcribed verbatim and entered into Nvivo 9 for thematic analysis.

Findings. The key themes represent patterns of nursing work as; system work, relationship work and patient work. Whilst nurses lacked a coherent understanding of patient navigation as a concept, the way they worked had some elements in common with professional navigation models.

Conclusion. Further research involving older people in co-designing patient navigation approaches in Primary Health Care is needed to inform these types of service development and translate action from existing health policy.
Key words: long term conditions, older people, patient navigation, primary health care
SUMMARY STATEMENT

Why is this research needed?

Patient navigation models are well developed and supported by a growing body of research for patients with Cancer.

There is a lack of research in Primary Health Care on patient navigation models for older people with multiple long term conditions.

There is little evidence regarding the extent to which current work patterns of nurses providing care for this patient group fit with professional patient navigation models.

What are the key findings

Patterns of nursing practice were identified that reflect system work, relationship work and patient work.

Although nurses lacked a coherent understanding of patient navigation as a concept, nursing practices were identified that had some elements in common with professional navigation models.

A particular need for education relating to the transition to end of life care and supporting older people with cognitive impairment was identified.

How should the findings be used to influence policy/practice/research/education?

Management and leadership practices that support nurses in their system work, relationship and patient work are required.
Further research involving older people in co-designing patient navigation approaches in Primary Health Care is needed.
INTRODUCTION

Internationally, there has been a shift away from a single disease management model to one which acknowledges that many patients now experience multi-morbidity. In the context of an ageing population, integrating services and achieving co-ordinated care for the burgeoning numbers of older people with multiple long term conditions has been referred to as a global challenge (Goodwin et al. 2013). There has been a call to increase the capability of the health workforce to address this challenge, with nurses being identified as a particularly valuable resource in this regard. Patients experiencing multiple health problems often require input from numerous different health services operating in an increasingly complex health system. This has led to a recognition that Primary Health Care should be the main navigation point for patients to support them in managing the complexity in the system (Nasmith et al. 2010).

Background

Patient navigation is a barrier focused intervention aimed at reducing barriers to health care for individuals and was initially introduced as a model to improve cancer care in the USA (Paskett et al. 2011). Fillion et al. (2012) has identified three types of navigation; self-navigation using online approaches, lay navigation involving a volunteer peer groups (Blickem et al. 2013) and professional navigation by a health professional. It is this last model which is the focus of the present paper. Patient navigation models have been argued to reduce the barriers to effective care, enable older people to feel empowered in the complex health care system (Palos 2011) and ensure ‘safe passage’ across the continuum of care from diagnosis to death (Case 2011). Initially navigation models were developed in cancer care and research into the role of the nurse navigator in this context has demonstrated the potential of this role to improve patient outcomes and, in particular to improve access to services and
empower patients to take charge of their own healthcare (Fillion et al. 2009, Lee et al. 2010, Shockney 2010, Paskett et al. 2011).

Primary Health Care has been identified as the preferred setting for the development of patient navigation models for patients with multiple long term conditions, as patients prefer care co-ordinated by Primary Care (Nasmith et al. 2010). However, a lack of engagement by GPs in the provision of coordinated care for people with multiple LTCs has been observed (Goodwin et al. 2013). Importantly, Primary Health Care nurses have already demonstrated positive outcomes in working with patients with specific long term conditions (Anderson et al. 2012) and GPs recognise the potential of nurses to assume an expanded role in relation to navigation (Waterworth & Gott 2011). However, a systematic review of navigation roles to support older people with multiple long term conditions found little evidence of the existence of navigation roles in Primary Health Care (Manderson et al. 2012). Various case management models were found to have been adopted for specific conditions and for high risk and/or frail older patients to reduce hospital admissions, but most of these were not based in Primary Health Care practices (Manderson et al. 2012). An examination of the extent to which navigation models of care are already part of the daily work of health professionals was also identified as an issue in need of further research (Manderson et al. 2012). In this context our study is therefore timely in exploring how nurses are currently working with older people with multiple LTCs and, in particular examining nurses’ perceptions of navigation both as a process and as a specific role.

THE STUDY
Aim

The aims of this research were: 1) to generate in-depth insights into how nurses are working with older people with multiple LTCs; 2) to gain an understanding of how nurses perceive professional patient navigation; and 3) to explore the barriers and facilitators to nurses adopting a navigation role in the context of Primary Health Care practice.

Design

Given the lack of previous research regarding the potential translation of navigation models developed in cancer care settings to the primary care context, a qualitative, exploratory study design (Holloway & Wheeler 2010) was adopted. Semi-structured interviews were conducted during 2012 with Primary Health Care nurses, District Nurses and Heart Failure nurse specialists who were all working with older people with multiple LTCs.

Sample

The participants (n=42) were purposively selected from three sources: 1) a database of nurses who had already completed postgraduate study in long term condition management at universities across New Zealand (NZ), as they had been involved in critically reviewing their practice and services and therefore constituted ‘key informants’ (Patton 1990); 2) a national network of nurses who were working in Heart Failure nurse specialist/practitioner (HFNS) roles across NZ; and 3) a national network of District Nurses (DNs). Participants were selected to ensure that both rural and urban areas of NZ were included and were invited by either letter or email. Our previous research (…..) and advice from the research advisory group identified the need to include the latter two groups of nurses. Heart Failure nurse specialists were included as an example of a group of nurses working across care settings.
(and increasingly in Primary Health Care) (Davidson et al. 2001) and District Nurses were included due to their significant role in caring for patients with LTCs, including providing end of life care (Walshe & Luker 2010).

Data collection

Telephone audio recorded interviews were conducted to access participants from different geographical areas. A semi-structured interview guide informed by the advisory group and a review of the literature was developed. Participants were asked questions regarding their experiences of providing care to older patients with multiple LTCs through the continuum of care from diagnosis to end of life care. Once the nurses had shared their experiences of working with older people with multiple LTCs, they were then asked about the navigator role.

Ethical considerations

The study was approved by the National Ethics Committee. All participants received written information and signed a consent form prior to interview.

Data analysis

Interviews were transcribed verbatim and entered into Nvivo 9 (QSR International Ply Ltd, Doncaster, Victoria, Australia) for thematic analysis (Thomas 2006, Bazeley 2009). This process involved reviewing the transcripts and audio recordings to check transcription; listening to the recordings also allowed us to take note of participant’s emotional responses (Anderson 2010). DR and SW independently coded several transcripts and following discussion reached a consensus on coding and emergent themes. Themes were then further analysed by SW and compared again across all the data sets. Strauss and Corbin’s (1998) framework of 6Cs; causes, contexts, contingencies, consequences, covariations and
conditions, was helpful to identify variations, influencing factors, nurses’ concerns and ways
the nurses’ addressed or did not address these concerns. An overall thematic framework
reflecting the patterns of nurses’ ways of working was developed.

*Rigour*

First, participants were selected from a range of nursing backgrounds and as interviews took
place alongside initial analysis we were able to test out some of our emerging ideas and
unanswered questions with subsequent participants. Whilst each participant had the
opportunity to review their transcripts, only three participants requested to do so and they
neither requested changes nor made any further comments. Initial coding and analysis took
place between DR who came from a psychology background and SW who came from a
nursing background. Questioning assumptions enabled differences and interpretations to be
highlighted requiring further review of data to reach agreement on themes. Further discussion
of themes took place between SW and MG. Presentation and discussion of the key themes
took place at inter-disciplinary research team meetings with BA, MG, JP and SW. Verbatim
quotes from the data are used in this paper to allow the reader to make judgements regarding
interpretation (Anderson 2010).

**FINDINGS**

The key themes represent patterns of nursing work as system work, relationship work and
patient work. Whilst nurses lacked a coherent understanding of patient navigation as a
concept and some were not familiar with the term, the way they worked had some elements
in common with professional navigation models.

System work comprised knowing the system to be a link person for the patient to other
people in the system. For some nurses this had involved changes in their own systems and
organisation to achieve the linkages that they spoke about.
‘We can take direct referrals from GPs to see patients and we’re really like a link between primary and secondary care’. (HF1)

Knowing the system enabled some of the nurses to be an advocate for the patient and their family; this enhanced communication and information sharing and ensured a timely, responsive service for patients.

‘I am forever on the phone to …….clinic, this patient was supposed to have an eye check-up six months ago, I’m just checking, are they in the system. Yes they are, they’ve got an appointment. So I have a lot of information about how the …….clinic works.

I ring the specialists, I have their phone numbers and I ring them when I need to know something. I don’t wait to go to the GP and then through the appointment system. I speak directly to the specialists’. (P9)

Some practice nurses had been involved in changing their own practice to make their role more visible to patients. Deliberately working in a more ‘patient-centred’ way involved the nurses explaining their role to the patient, including clarifying to patients that they could make links patients may require to other services or professionals.

‘We have a system at our surgery where new patients enrolling have a nurse consultation for a new patient and as well as taking all the general history and base line data. We would also advise them of the services we provide, areas where they might seek help and just saying that we are accessible to giving them assistance wherever and if we can’t do it then we can certainly help with that process of finding the person’. (P20)
Some nursing roles had been established to provide more in-depth support and advice to patients. Whist this largely affected some of the nurses who were working in heart failure specialist roles, funding in GP practices had also been used in different ways creating innovative roles. This enabled a nursing service to be reconfigured to achieve more person centred and cross boundary work.

‘There was some talk when my role came up and was first funded, because it’s funded through SIA funding, that it maybe could have been a social worker role. That navigator, that person would be doing exactly what I do. The advantage is that as a nurse I can go in and do some of the assessments as well’. (P11)

The ability to maintain regular contact with patients was seen as a key aspect of being able to support patients in managing their multiple LTCs. Regular contact enabled the nurses to get to know the patient and develop partnership working with the patient and family members.

‘Seeing the same people or the same groups of people works very well, you can build up a relationship, a trusting partnership’. (P20)

In contrast, participants reported that the way nursing work was organised could impact on the relationships that nurses valued and their knowledge of the patient over time. This in turn was seen to impact on their efficiency as they had to spend more of their time getting to know the patient.

‘If you’re going to rotate the nurses it’s going to take them a little bit longer to pick up on things. If you’ve got the relationship you can actually pick up on it quicker. You know when
you arrive if something’s not right and you don’t have to do all that ground work because you know. That’s a barrier, the time factor’. (DN8)

Whilst some of the nurses working in General Practice felt they had encouragement and support for their role from their General Practice team, workload issues and the limited time they had to spend with patients was highlighted as problematic.

‘Don’t get me wrong practice nurses that do a practice nurse role do too many things in a very short time. You need someone with more time than fifteen minutes. I think there is a difference between a practice nurse who does practice nursing and someone who is specifically aligned to a condition’. (P8)

For nurses themselves, absent or inadequate communication from other health professionals and services, as well as documentation systems, added further complexity in trying to manage patient care.

‘Because some of that (information) has got to sit in their notes, in the client notes, that’s held at the practice. Bear in mind all these don’t talk to each other. …..If we had one system that could access both primary and secondary it would be awesome’. (DN2)

Participants identified that having systems in their service or practices that promoted integrated was particularly valuable.

‘The key thing is communication and that’s within the team. Not just nurse – doctor, it’s reception, the practice manager and the whole thing behind that is navigation too, the practice management systems’. (P17)
Participants also described how, in some cases, patients could be missing out on care; they referred to this as ‘falling through the gaps’ as patients were not referred to appropriate services. There was an acknowledgment that currently no one individual assumed responsibility in managing the patient across the health system. This had implications both for the patient and health professionals themselves.

‘People work in their own little area and don’t get their heads around that it’s the same patient having to go through all those areas and that a point of contact for that person might be really helpful for both the patient and the clinicians working in the area’. (P10)

The wide range of services accessed by patients across multiple providers meant that having an in-depth knowledge of the system and the services was seen as essential to provide information to patients and make the links. Participants identified that this was not just about health and social services in general, but also having wider knowledge of their local community resources.

‘We have good services in our area it’s just being aware of them. I’m often in the community doing stuff and I volunteer for another organisation so I have my ears and eyes open to different things. I often take things from my outside world to my work role. And they’re how did you find out about this? But I don’t know as a nurse, if you’re just doing your nurse role how you do find out about that stuff”. (P6)

Patient/client work

Knowing the patient as a person and the difficulties they might be encountering as older people living their lives was important to the participants to meet their individual needs. The
complexity for patients was not just about living and adapting to manage their multiple LTCs as an older person. Nurses spoke about understanding that other things were also impacting on the patient as an individual. This meant they were careful to avoid being judgemental when the patient had to make adaptations e.g. altering timing of medication or not following professional guidance and advice.

‘You have to take into account the other things that are impacting on this family and how that might impede their decision if they don’t turn up for their appointments or if they’re not complying. Sometimes the issues aren’t always about the patient, they might be about someone else. They’re more concerned about what’s happening to someone else rather than themselves’. (P11)

‘If I’m trying to achieve health with my patient’s lungs and they’re living in a flat with black mould on the wall and a huge black tree not letting sunlight in, why would I waste time. I’m absolutely wasting patient’s time and government money if I’m not looking at those other issues’. (P9)

Nurses who carried out home visits valued seeing the patient in their own home environment and saw this as critical to providing patient centred care, particularly if the patient had difficulty accessing the GP practice. Most of these nurses were DNs, but some PHC nurses and HFNS were also carrying out home visits and valued the opportunity to assess the patient in their own home environment to gain further insight, knowledge and understanding of the patient and, if relevant, their family.

‘He happens to have cellulitis, so the reason for our referral was his cellulitis. He’s lost the integrity of the skin, both legs, so he needs to have dressings. The referral was specifically for
dressings, but when we go in we see that he’s got other chronic disabilities like mental health, anxiety, stress, Parkinson’s and really the immobility that’s associated with that. He’s got a wife who looks after him and who’s struggling’. (DN11)

There was recognition that, to be effective, working with patients with multiple LTCs requires an approach that focuses on patient empowerment and enabling the patient to self-manage.

‘Teaching people how to work with a patient so the patient’s setting a lot of goals. I’d hate to see the nurse taking over and going, I have to organise this and I have to sort that, it’s about teaching the patient that there’s still things they can manage themselves and what goals do they have’. (P16)

‘They feel confident when they go there, because if they’re not confident it adds to their disempowerment’. (P9)

Whilst some of the nurses were working in specific roles supporting people with long term conditions, there was recognition that it was complex and demanding work and required more time. That not all nurses may want to work with older patients with long term conditions was also acknowledged.

‘I know we struggle to get people interested in working with long term conditions, meaning nurses and clinicians, doctors’. (P9)
Nurses also identified specific challenges in supporting older patients with cognitive impairment and depression.

‘I think we deal badly with cognitively impaired people. I think it’s frightening, I frequently see them frightened and overwhelmed and I’m very uncomfortable with our management of cognitively impaired people’. (P10)

Relationship work

Relationship work with health professionals and service providers was seen as critical to providing patient centred care. Relationships had to be built, developed and sustained over time.

‘You want to have consistency. I think that if we can fine tune that and, get those relationships because we want to all be on the same page. Whereas sometimes you find oh they’ve got that service in there, I didn’t know about that. Someone else is doing something else and it’s kind of you’re recreating the wheel in a way’. (P17)

‘It’s one of my key skills that I’ve learnt to develop. Building the relationships will get the support and the resources in to the patient’. (P11)

For some of the nurses this relationship building was highly problematic and in some instances was not occurring to the extent that the nurses identified was necessary to provide the care that older patients with multiple LTCs required.
‘There isn’t actually a lot of communication between the GPs, practice nurses and the district nurses so you start to lose a bit of track of where they are medically. And by that, you know, then it's not up until there's a crisis that you actually, you know, revisit the whole co-morbidities again’. (DN12)

Patient navigation in Primary Care

Primary Care was seen as the central place where patients could be supported to navigate the system, building on the work that some of the nurses were already doing. However, some participants identified that having a specific named nurse as the navigator would be perceived as a threat to other nurses or health professionals and the change would be resisted. This reflected the number of specialists involved in the patient’s care and management and the fact that a ‘my patient’ attitude was still prevalent.

‘But how would the hospice feel about this, because they would see themselves as navigators. You’ve got to be very careful because you’ve got regional respiratory nurses. They may see themselves as the navigator’. (D4)

Several participants viewed the navigation role as a case manager role and not necessarily a nursing role, whereas others suggested a distributed or team model of navigation.

However, for some nurses taking on what they referred to as ‘additional or extra work’ would be problematic, illustrating that they saw the process of navigation as extra work and not part of their everyday practice with patients. District nurses identified that, whilst continuity of care was important to them, they believed the system they had in place worked well and any additional work which they associated with navigation e.g. following up on referrals would
be problematic if the structure did not change. The risk of adding more roles or layers to an already complicated health system was identified.

‘I think in some way you’ve got to be careful actually that you don’t involve another layer’.

(D4)

DISCUSSION

This study has shown how nurses’ work with older people involves system work, relationship work and patient work. Differences in practice reflected the nurses’ role, context, views of navigation and the barriers they faced to working effectively.

Nurses in this study identified significant barriers that older patients with long term conditions were experiencing to manage their lives with multiple LTCs, such as access to services and understanding information from different health professionals. How the nurses assisted patients in removing barriers showed the type of work that some of the nurses were doing for and with patients. These could be classified as instrumental and relationship interventions (Pascal et al. 2011). Instrumental interventions are task focused, such as assisting the patient with transport or financial issues. Relationship interventions, promote continuity of relationship and aim to support the patient and family in managing relationships with other health professionals or services and so enhance integration and co-ordination of care. Our study participants showed evidence of providing both type of interventions.

Navigation encompasses information support, linking to other resources across the health system, supporting decision making, providing emotional support and facilitating practical assistance (Pedersen & Hack 2011). Whilst all of these practices were identified in this study, there were variations which would have an impact on patient outcomes or care if nurses were
unable to achieve them. It could be argued that all of the elements in the navigation role are consistent with what nurses have traditionally referred to as the process of co-ordinating care. However, navigation is not only about coordinating care and for some nurses in this study they had a limited role in care co-ordination as their work was largely task focused and limited by organisational and practice cultures.

Some participants were very clear about their role in working with older people with multiple LTCs and they were highly motivated to work with older people who had multiple long term conditions, but for others role ambiguity was evident. For some there were time and workload issues that presented barriers to the ways they wanted to work to support patients in a complex health system and to minimise what May et al. (2009) referred to as ‘disruptive medicine’.

All the practice nurses were employed in a GP practice that operates as a business model and the constraints of this system on their nursing role and developing their practice have been identified in previous research (Ehrlich et al. 2012). Our findings resonate with previous studies identifying the barriers this presents to nurses who want to work more in line with the navigator role (Ehrlich et al. 2012). Referral to other services and liaison with other services and health professionals was a common practice, but once again the extent of this varied. For some nurses there were gaps in the availability of services that could be provided, but also gaps in knowledge about what services were available. This illustrates that at some points in the patient journey there are practices to support patient navigation, but that these are not consistent (Hauser et al. 2011).

Patient empowerment is a key desired outcome of navigation models and it was evident in this study how some nurses were using ‘empowerment strategies’ (Laschinger et al. 2010). Virtanen et al. (2007) refer to ‘empowering discourses’ and for some of the nurses,
empowering patients was seen as a core part of their role; and was reflected in their ‘patient work’. Virtanen et al. (2007) view empowerment work as a ‘demanding nursing intervention’. Indeed, overall and in line with Anderson et al. (2010) and Ehrlich et al. (2012), our research has highlighted that supporting patients with multiple long term conditions is challenging and complex work. Multimorbidity presents patients with a high treatment burden that results in challenges for patients’ self-care and self-efficacy (Hughes et al. 2012, Dickson et al. 2013), so it is not surprising that nurses with expanded capabilities are required to support patients with these challenges.

The research evidence for patient navigation beyond cancer care is limited and in some situations has been confined to specific episodes of care rather than the continuum of care. Other models such as case or care management have been found to promote some similar outcomes for patients, but have tended to focus on high-risk, high-cost populations or the frail elderly (Oeseburg et al. 2009). However, despite the case management model being advocated as an approach for patients in high-risk groups and there being some similarities between case management and navigation models, the research evidence suggests that patient navigation is unique in reducing healthcare disparities (Vargas et al. 2008). This is particularly significant when thinking about optimising care for older people as ‘ageism’ is still prevalent in most developed countries (Gott et al. 2013). Rather than a case to be managed, patient navigation models focus on critical outcomes, notably reducing barriers and empowering patients, outcomes not typically associated with case management models where the emphasis has been on ‘managing the patient’, rather than ‘working with the patient’ (Oeseburg et al. 2009).

Working with complex patients is seen as an advanced role (Ehrlich et al. 2012). The nurses in this study identified the need for further education. Certainly in the literature education for
the role is varied and models have provided some form of educational program to support navigators. It is recommended that a standardised educational program is provided for navigators (Wells et al. 2008). A particular need for participants was identified in relation to education relating to the transition to end of life care; indeed, all participants identified a need for further education to support them in working with patients and families at this time.

Although there is now accumulating evidence about the role of nurses as patient navigators working with cancer patients, there is a lack of research on patient navigation models for patients with other long term conditions, importantly those who have multiple morbidity. This paper offers an important contribution to understanding the ways nurses are working with complexity. Our findings suggest that there is the potential for PHC nurses to work as navigators with older patients with multiple long term conditions. Moreover, having a nurse rather than another health professional as a key ‘navigator’ could promote effective team work (Ferrante et al. 2010), enable nurses to lead change (Institute of Medicine 2010) and contribute to the call from the World Health Organization to improve primary health care for older people (WHO 2004). Further research is however needed if such models are to be implemented successfully in nursing practice.

Limitations

Purposeful sampling was used to recruit PHC nurses who had completed postgraduate study in long term condition management at universities across NZ and their perceptions may have been different from nurses who had not completed further study. The study was reliant on nurses’ verbal accounts of their experiences and no observation of their actual practices was employed. The perspectives of older patients regarding nurses’ work were not captured.

CONCLUSION
The demand for nurses who can meet the needs of older patients with complex health needs in a complex health system is increasing. Patient navigation models developed in Primary Health Care practice offer the opportunity for nurses to fully develop their role as navigators. On the basis of our research, there is a need for role clarification and further preparation of nurses to achieve the system work, relationship and patient work we have identified as needed for future care of and with older people. Further research involving older people in co-designing patient navigation approaches in Primary Health Care is needed to inform these types of service development and translate action from existing health policy.
References


National Health Committee (2007)*Meeting the needs of people with chronic conditions. Hapai to whanau mo ake ak tonu*. National Advisory Committee on health and Disability. Wellington. New Zealand.


Table 1: Participant demographics

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