**Abstract**

The aim of this study was to examine the feasibility and impact of a group intervention by Community Matrons to support those living with multiple long-terms conditions. Little evidence exists as to how the role of the Community Matron (CM) should be delivered to effectively enhance disease self-management and levels of self-efficacy for the service users.

This qualitative participatory action research study explored the use of group work as a method of intervention by CMs. A purposive sample of twenty nine participants was recruited. Each patient group had 8-10 participants, led by a CM working in both the researcher and practitioner role, operating over 12-month period. Data was collected by participant observation, researcher reflexive account and interviews. Grounded theory method was used to systematically analyse the data.

Three main data categories emerged; 1) comparison by patients that leads to re-motivation of the self; 2) learning, leading to enhanced self-management techniques through storytelling and understanding of each other’s experiences; and 3) ownership that resulted in the cognisance, self-awareness and insight into the support group they were based in and how it benefited them. The core category of ‘*Taking back the self - understanding the whole*,’ conveyed the impact that this care delivery method had upon re-adjusting the balance of power between health professional and service users and its consequence in refreshing and improving LTC self-management and the patients’ related self-efficacy.

It was concluded that CM intervention using a model of group learning can lead to more effective and efficient support, through improving self-efficacy and related patient self-management ability.

**Key words**

Community Matron, long-term conditions, group learning, self-management, self-efficacy, action research, very high intensity service users.

**What is known about this topic?**

* The number and complexity of those living with long-term conditions is increasing.
* The intervention methods employed by CMs for supporting very high intensity service users (VHIU) have received very little development in the clinical or research field.
* There is little evidence that supports a self-management model that is specific to the cohort of patients managed by Community Matrons.

**What this paper adds?**

* An intervention model that meets social/health needs improves patients’ self-efficacy and their ability to engage effectively in their disease self-management.
* Through facilitated groups patients can work collaboratively, shaping the care delivery appropriate to their identified needs.
* New evidence that health behaviour change for VHIU can be achieved through group intervention, facilitated by senior community nurses.

**Introduction**

In England, more than 15 million people have a long term condition defined as a health problem that cannot be cured but controlled by medication or other therapies. This figure is set to increase over the next 10 years, with people suffering 3 or more conditions at once (DoH 2005). Care of people with long term conditions (LTC) accounts for 70% of expenditure on health and social care in England (DoH 2013a, 2015). By 2035 it is projected that those aged 65 and over will account for 23% of the total population (Office National Statistics, 2012).

Disease self-management has been seen as a means to reduce the service and financial burden of effectively supporting people with LTCs by equipping them with skills to manage their health. In the 1990s, responding to studies demonstrating behaviour modification through disease self-management programmes, its popularity as a mechanism for reducing the cost associated with LTCs led to the development of the Expert Patient Programme (Lorig et al 1989; 1993; 1996).

# Background

In England, the launch of the Community Matron (CM) nursing role was a national policy response to this challenge (DoH 2005b). This policy initiative was guided by pilot projects (Pfizer 2004; Matrix Research and Consultancy Ltd 2004; Colin-Thome and Belfield 2004; United Health Europe 2005) that enabled more effective management for people with multiple LTCs by reducing unscheduled care (Drennan et al. 2011). The role was viewed as a means to reducing the admission rate to the acute setting by 5% for this precise group defined as very high intensity users (VHIU) (DoH 2005b). To devise the best therapeutic outcome the practitioner and patient should work as together as partners to develop effective self-management (Clark and Gong, 2000); this should include physical, psychological, socio-economic consequences.

 The promotion of self-management is seen as intrinsic to health systems and of positive benefit to the individual, rooted in an espoused ideology of empowerment and individualism. Current evidence reveals the positive clinical value of disease self-management amongst those living with LTCs. A Cochrane systematic review on the clinical value of disease self-management mediated through education revealed positive impact through disease specific management, but little evidence with a generic disease application (Foster et al. 2007). The importance of ensuring the intervention is tailored to the condition was highlighted (de Silva 2011). For example, structured patient education can be beneficial for people with diabetes, while people with depression may benefit more from cognitive and behavioural interventions.

The counter argument for the concept of self-management practice may be driven by “fiscal considerations” (Anderson, 1996, p 702). Kendell et al. (2010) report that self-management is seen as a process for the educating of people that are ‘in need of instruction,’ placing the service user within the passive and dependent role, with the health professional as the expert. The measures put into place to solve the ‘burden’ of LTCs are essentially financially driven to reduce the cost within the health care system. By ‘solving’ the burden emphasis is placed on managing the condition putting the disease first, the disease remains the central focus point. Governments seek to endorse self-management as the way forward through offering freedom, choice and opportunity but Kendell et al. 2010 argues that patient choices are limited by hidden ‘rules’ about what is deemed to be a health behaviour; the actual control over these rules are allocated to health professionals and assumptions are made aboutthe capacity of all individuals.

It is pertinent to acknowledge that both schools of thought exist between self-management and fiscal considerations however evidence does suggest that it is of benefit to service users. The King's Fund (2012) identified gaps in delivery quality calling for patients to be offered the opportunity to co-create personalised self-management interventions.

**Method**

**Aim and objectives**

Aim: To examine the feasibility and impact of group intervention by CMs to support those living with LTCs.

Objectives: 1) To explore processes and methods by which combining a social learning environment with a health directive can enhance the self-management of those living with multiple LTC through adopting a Social Cognitive Theory perspective (Bandura 1996).

2) To explore the processes by which patients with LTCs within a group setting participate to develop ways of supporting one another collectively, within a social learning environment over time.

3) To examine the outcomes of an action research study for those living with LTCs in relation to their self-efficacy and disease self-management following participation within a social learning environment, facilitated by CMs.

**Design**

An action research approach was used to investigate a small specific group of service users and their development in groups over time. Applying Lewin’s action research model (1946) enabled a bottom up approach to research design driven by the inclusion of the service users. Cassell and Johnson (2006) highlight that the emphasis in action research is on the democratic process of engaging with all stakeholders in determining the nature of change. There are indications that this process of research can empower patients (Titchen and Binnie 1993).

Three action research cycles were identified. Three iterative cycles developed through the study that aligned themselves naturally to the three data collection points of six and twelve months. The six and twelve month data collection points provided the scope within the design to evaluate the data, present it to the participants and then to move on to the next cycle. The data phases within this research study were designed to be collected in a sequential order, ensuring that each data collection point served to enlighten subsequent data collection, using theoretical sampling. The sequential order of data collection also served to ensure that data feedback could be given to the participants to ensure the on-going trustworthiness of the data.

 **Sample Participants**

A purposive sampling method was applied which is commensurate with action research. Twenty nine participants were enrolled within this action research study following ethical approval, ranging from 64-95 years (mean age 72 years) and 62% female and 38% male. Inclusion to the study was based upon the participants having had their care delivered by a CM, being accepted onto their caseload and meeting all of the host organisational criteria of VHIU.

All participants were sent a participant information booklet and a letter of invitation to the study; 110 invitations were distributed. Each contact was followed up 4/6 weeks later with a personal phone call to provide further explanation to the study and organise consent for recruitment. From the initial call for participants, 35 individuals expressed an interest in coming into the study. The final number that consented for the study was 29. Details of the study inclusion and exclusion criteria are illustrated in table 1. The sample reflected heterogeneity by age, sex, ethnicity and type of chronic disease.

Table 1. Inclusion and Exclusion Criteria

**Nature of group intervention and operation**

All participants lived with at least two or more LTCs. Participants were placed in groups of 8-10 by their geographical location. The groups were accommodated in local church halls away from the traditional medical environment. The groups ran on a fortnightly basis. Participants attended the group to receive their clinical care, which replaced a home visit, unless they were too unwell. A variety of learning methods were developed. A key feature of the groups is that their development drew upon the theoretical work of Bandura (1997) on social learning, in which self-efficacy (in this case of self-management) can be developed through learning by vicarious experience.

As the CM and researcher, I took on a facilitative role within the groups. Participants understood that the groups were formed as a way of providing care and learning. Time was needed to get to know each other and build confidence to share and understand each other’s challenges. Trust was paramount in the groups and for this to develop; a facilitative approach worked to enhance this. The focus was always on what the participants wanted to address regarding their health. This required the skill as the facilitator, to listen to conversation and establish important points to focus on. A key driving principle was to support the group to find its way to develop without any set agendas and to take the lead on identifying topics that were important to them and their support. If the issue required input from other health professionals, this was sourced to complement their group self-management teaching.

**Data collection**

Data was collected between the dates of December 2011 and July 2013. A sequential study design was employed. This was characterized by iterative, reciprocal and interdependent data collection (Tashakori and Teddlie 2009). The study was organised into two operational data collection phases.

The qualitative data collection of phase one was implemented at 6 months with participant semi-structured interviews and phase two was at 12 months with follow up interviews with the same participants. The use of multiple data sources was used to corroborate evidence, enhancing triangulation and so supporting the study’s validity/credibility (Creswell 2007).

From each of the four study groups, two participants were randomly selected to provide the interview data (n=8). The interviews were conducted within the participants’ homes and were semi-structured to explore and develop a deeper understanding of how those living with LTC participate to support one another (or not) within a social learning environment. Further exploration was also given as to whether or not the group experience enhanced or not their self-efficacy in their disease self-management.

The interviews at phase one and two were digitally voice recorded. Early thoughts were captured by the researcher. All interviews were read through then read again drawing codes from the data. A continual ‘sense check’ of the data was made to ensure that what came from the data was a true reflection of the emic or participant perspective voice and not the etic stance of the researcher. Rigour was achieved through subjecting the coding process to random analysis using an audibility check by a peer to ensure that the focus on the emic position and the consistent application of coding rules.

Participant observation data in the participant as observer was collected throughout the study using structured field notes. Each group session that took place provided a rich observational data set of how participants interacted with each other to provide learning enhancing self-management. As grounded theory analysis was applied to the data set it was important not to be selective in my data observation trusting that the chosen analytical method would provide this information post analysis.

**Ethical Considerations**

The study received a favourable ethics outcome through the Southampton and South West Hampshire Research Ethics Committee (B). NHS Trust governance was given approval by Southern Health NHS Foundation Trust.

**Data Analysis**

A Grounded Theory analysis was used to guide applied to the data (Glaser and Straus 1967). The data collected was digitally voice recorded and transcribed by the researcher to immerse into the data and begin to gather some early unsaturated open codes. The aim of this process was to ensure a full emersion and engagement with the data. Computer aided NVivo 9 analysis software was used to assist with the management and organisation of all the qualitative data. This also allowed for memos and notes to be written and stored throughout the analysis phase. Rigour was achieved through subjecting the coding process to random analysis by a peer to ensure that the meaning gathered from the text was based on the participants’ or emic stance. Open coding took place though line by line analysis, breaking the transcript down and identifying concepts embedded within the individual statements. A re-read of data ensured that previous coding was consistent allowing for further exploration of any overlooked codes.

The codes were arranged into categories and it was anticipated that some codes would cross from category to category. The category terms used reflected the participants’ language. Constant comparative method was undertaken to compare similarities and differences amongst emerging concepts and sub-categories that existed to generate properties (sub-categories) of the emergent categories. The process of coding and categorising continued until saturation occurred when no new information on a category was found and the key links between the categories were firmly established. At all times the analysis was ‘played back’ to the participants in order to ensure that the interpretation made by the researcher was closely aligned to the participant’s narrative and their emic perspective.

# Findings and conceptual development

The elements of the substantive grounded theory generated comprised of three principal interrelated concepts or categories namely; *comparison, learning* and *ownership.* Thesecategories and their interrelationship illustrated the process by which enhanced self-management and self-efficacy was achieved by participants within the facilitated group learning context. Each principal category is now examined in turn and in due course their interrelationship is outlined.

***Comparison***

The concept of ‘comparison’ refers to the process of evaluation between and by participants. Through applying a group method of care delivery a process of re-motivation was triggered. This consisted of the immediate impact on participants seeing someone else in the same position that was often perceived as ‘worse off’ or ‘better off’ than themselves. Inspiration was gained followed by cognisance and understanding of the self. Regular group attendance provided reinforcement and helped to sustain self-awareness and motivational behaviour. Some of the properties of this category are illustrated briefly below by narrative data excerpts.

*“When you see other people worse off you realise that there is nothing to be afraid of and you carry on, you keep going.”*

*“Well I think you do compare your lives to one another and I feel that I’m a bit behind for the simple reason, they might be worse off than me, but they can walk and go to the toilet.”*

**Attention gaining:**

*“One thing that struck me straight away.”* (Study Participant 2)

**Inspiration gaining:**

 *“That did impress me.”*(Study Participant 4)

**Learning through understanding:**

 *“If he can do it so can I.” “I needed to give myself a kick up the backside.” “I know about that because my brother died of it.”* (Study Participant 7)

**Re-motivation and reinforcement:**

*“That’s when I started thinking, come on let’s get moving”. “He was an inspiration.”* (Study Participant10)

These elements were seen to interact as a process; this is illustrated in the diagram in Figure 1.

*(Insert)* Fig. 1 Pathway to re-motivation in the group learning process.

***Learning***

The principal category of *learning* was construed as being achieved through the group work, where participants learnt from each other through story telling: this was used to validate experiences and also to seek to understand why they felt and acted the way they did.

*“Well that would be nice because you see again you are talking with each other and learning from each other because some have different outlooks than you and you learn or they may have done something or tried something different and you can think, “oh, well I could have a go at that” because I’ve got the same, more or less symptoms, I could try that myself.”*

Through this pathway participants began to understand themselves; this process led to enhanced learning about themselves and their lives and how their disease self-management became a part of this social dimension of their lives. This socially and personally situated experience differed from the very disease focused self-management treatment that they had previously received. This approach encompassed a psychosocial element to their therapeutic treatment and used the experience of others to work in a partnership style of providing care with the health professional illustrated in figure 2.

(*Insert)*Fig 2: The Pathway of enhanced self-realisation through learning together

***Ownership***

This principal category conveyed how participants began to take ownership of their groups and through participation develop a sense of being a social group. Participants conveyed understanding that their disease management required a method of care that encompassed and integrated all dimensions of their lives for them to begin the process of taking back greater control in managing their health. This increased degree of self-awareness of the need for and scope of disease self-management led to greater understanding of self and greater ownership of their health management. An emphasis that emerged throughout this study was one of a more power-neutral relationships being established between the health professional and service user, as a member of a socially supportive group.

*“We all understand what each other are going through, we don’t have to explain or hide. It is open and free conversation with an understanding.”*

*“I have found that through group methods of care delivery, I have learnt more about the motivation of my patients. I am seeing them in a different, more whole light then just managing aspects of their health in a home one to one remit. Listening to them discussing their lives together gives me a clearer insight into how they manage their life. When I see the participants in a group I get such a different perspective on their lives, the impact of their health on their everyday life and tasks. To visit at home I have become medically orientated, to be present in a group opens my perspective to their world in a whole different way.” (Reflexive Diary)*

 Through this alternative case-management approach, the underlying psychosocial aspects that affected how the individual lived and managed their LTCs could also be addressed and embraced. This aided the adaptation needed to integrate their long-term condition more effectively into their everyday lives.

**Development of the core category and basic social process**

Through the examination of each of the key categories and their interrelationships that emerged from the data, further insights were obtained into the process of gaining support in self-management through the group learning context, supported by a CM. The core category captures the central concepts and this reoccurs and emerges as a pattern across the data and links the other categories. The emergent basic social process that developed identified a new learning process amongst patients that invigorated health behaviour change and helped them to adapt within a social milieu to living with multiple LTCs. The overall emergent working hypotheses revealed strong interconnections between all three categories, which are reflected in the core category below. Participants used ‘storytelling’ as a method to enhance their understanding of themselves and their health behaviour. Learning derived from a comparison process enhanced a level of ownership of the ‘self’ and a strengthening of group bonds.

**The core category: ‘*Taking back the self - understanding the whole***

The core category depicted the central idea of ‘*Taking back the self - understanding the whole’* referred to the participants using the group experience to learn about themselves and gain a new understanding about their disease process within a personal and social context. This new knowledge was acquired directly from taught and indirect learning. The former was initially facilitated by the CM then picked up by the group with their assistance, whilst the latter was achieved through comparison within the groups, improved confidence and a wider understanding of the self with regard to disease self-management. The group was used as a means of triggering self-reflection and subsequent learning that developed and sustained their health maintaining activities.

The core category evolved from the principal categories and revealed a renewed vigour by the participants in the group that led to them gaining increased levels of motivation in their health behaviour. This outcome was achieved through the learning process and experience that took place through meeting as a group co-creatively. The interrelationships operating within this key social process invigorated the process of disease self-management and the self-efficacy of those participating in the group intervention.

The research findings revealed that there was more to case-management of LTCs and the self-management of disease than just a health professional disease dominant focus. Through this model of care, the balance of power could be re-established. Driven by the service user *(self)* the outcomes of the traditional professional driven model of frustration, confusion, denial and lack of ownership of the self can be readdressed. Through the course of the research study the power balance between health professional and service users shifted. Change was evidenced through the greater focus on the *‘self’* there was an improved sense of empowerment that came from them as a group and as individuals*.*

*“For us the doors have closed, no one wants to know us. This has given us hope; the door has opened a crack and light is at the crack. The door is no longer closed.”* (Study Participant 18)

Health behaviour change occurred through improvement in motivation levels and perceived self-efficacy levels; this led to improved medication concordance, fatigue management, understanding of their disease and specific improvements with disease self-management, such as with diabetes and respiratory conditions. Participants came to the revelation and understanding that their lives were not just about their disease management, their disease was located in the context of their personal and social lives. Greater self-awareness was enhanced where self-management support was not just about being *‘seen’* by a nurse or a doctor but a process of self-adjustment within a social context; and one of finding the *‘self’* within the context of their LTCs.Choices and decisions that they made were impacted upon through other external psychosocial factors such as guilt, knowledge, understanding, symptoms, fatigue, motivation, their family and carers as was recounted by the group participants; for example:

*“It’s not just the physical part, it’s the psychological.”* (Participant 10)

*“You have to understand the whole before you make a change.”* (Participant 12)

These codes identified that participants had had the opportunity to explore that their problems were not just physical ones. The groups provided time to explore this concept and identified its equal importance to their physical symptoms.

**Discussion**

This study provided the participants with the ability to take back control of themselves as an individual through this group intervention. This was achieved through the co-creation of a new model of intervention facilitated by a nurse within primary care. Through collaborative working between participants and the researcher/practitioner in an environment co-created and driven by them, a new sense of primacy was created with participants being free as individuals to adapt their lives with a LTC, through interaction with others in a similar situation, rather than just service users whom required case-management.

Participants in the groups had a renewed purpose, through learning with others that was motivating and enabling, revealing a greater understanding of the treatment choices that they had. This helped to personalise and humanise their care as people living with a chronic health problem, as a situation that could be adapted to through group learning. For the study participants the power balance shifted from a case management approach that had left them de-motivated and frustrated, to one that offered hope and a sense of regaining the self, allowing for renewed optimism and behaviour change. This is consistent with Todres et al (2009) theoretical model of the humanisation of health care that applies a patient centred approach to care.

This study provides valuable evidence regarding the operation and effectiveness of a community nursing based facilitated intervention model that promotes active patient engagement in social learning groups and how this may optimise support for those living challenging lives with multiple LTCs. Festinger’s (1954) classic social psychological work identified the processes and strength that self-comparison in social groups can assert. Applying the concept of social comparison, as a tool for disease self-management is under researched. No current evidence has been identified that links the benefits of the process of comparison of one’s own health and adaptive state to that of others in a similar situation through an enhanced level of adaptive social learning for those VHIU living with LTCs.

This group method of intervention provides an effective approach to primary care delivery for the VHIU patient population that can be applied to the role of the CM in support of those requiring LTC care. We believe the group model of support through senior community nurses is worthy of wider implementation in practice and accompanying evaluation.

To achieve this at organisational level, certain fundamental requirements will need to be addressed. One key element is the need for training and development for health professionals in group facilitation underpinned by Social Cognitive Theory. This study focused on the use of group work in which the role of the facilitator is pivotal and this was evident in this study. Specifically, education for health professionals is recommended with content to include; working with groups facilitating social learning directed towards self-management, a recovery and rehabilitative focus and a holistic orientation that helps to integrate the person and their lifestyle with their illness experience. There is a need to ensure that nurses sufficiently understand the key social processes that developed within the groups through this study and how they may impact on the participants’ self-efficacy and in turn their disease self-management ability.

Service integration is key in health and social care policy (DoH 2011a) and this has been a continued goal in primary health care for over a decade (Galvin et al. 1999). This model of social learning could be enhanced through an integrated model of care that encompassed not only physical health but mental health care. The government’s mental health outcomes strategy “*No health without mental health”* places considerable emphasis on the connections between mental health, well-being and LTCs (DoH 2011a). Naylor et al. (2012) advocate that the way forward for the care of those with LTCs is through the integration of services that address and integrate both mental and physical health. Co-morbid mental health problems raise the cost of care by 45%, an estimated cost of £8-£13 billion in England annually. A closer more integrated approach between physical care and mental health care can serve to improve service user outcomes and could enhance the model researched. Services for supporting the bio-psychosocial needs of those with LTCs require further development and efficacious models of this integration remain scarce.

Consideration should be given as to how the on-going implementation of this study could also link with community volunteer organisations, compared with professional facilitation; there is scope here for further research. There is the potential to form partnerships working with other volunteer agencies to assist in the provision of the *‘social framework’* (DoH 2016).

This study offers the evidence of a potentially more cost-effective model of health care delivery for VHIUs, but this needs verification through heath economic analysis. By inviting the service user to a central point to have their care delivered as a cohort, travel costs to individual patients were reduced for NHS staff. This in turn had the effect of enabling a release of CM time with the potential to achieve further reduction in unscheduled care admissions through group intervention rather than that organised on an individual basis alone.

Further studies are required on this group intervention self-efficacy support model on a larger scale to further validate the transferability of this study’s findings. This study aimed to deepen understanding of the process by which self-efficacy and then self-management may be developed through social learning; however, it did not apply formal evaluative measures to examine the relationship between the group intervention module and specific clinical outcomes in a controlled situation. Further longitudinal research could apply clinical outcomes measures to this intervention to explore potential clinical outcome improvements. As a method of enhanced case-management this model has the ability to adjust service impacts of VHIU by reducing GP visits, unscheduled admissions and through a more efficient method of care delivery release, CM time to provide further unscheduled care interventions.

**Limitations**

The sample size can be identified as typical of exploratory qualitative studies. Data collection was extensive over time and through a process of theoretical sampling and by seeking theoretical saturation, the quality of the data derived was enhanced suitably to address the research question. In the role of researcher/practitioner a balance had to be pragmatically implemented. Given the reflexive stance taken within the study, it is recognised that no social researcher can be completely objective (Charmaz 2005) but reflexive actions taken during the study to acknowledge this and provide transparency help serve to offset any impact on the credibility of the data. A reflexive account provided an on-going critical narrative of my place within the study and an open and earnest account of the many different ways of how, as the researcher, I aimed to deliver a transparent approach to my placement in the study as facilitator and analyst.

The credibility of this study has been demonstrated through the emic perspectives of the research participants, study background and through the analyst’s total immersion of the research data. The action research approach that was employed throughout the study ensured that participant engagement was foremost. It enabled ‘playback’ as a way to audit the data collected ensuring that the on-going mutual clarity and understanding that was developing through the data was shared with all participants.

**Conclusion**

The care delivery or intervention methods employed by CMs for supporting those living with complex LTCs has received very little development in the research field. The strategies employed have not followed an evidence based protocol; individual home visiting has continued as the dominant model without sufficient questioning of the most effective model of care delivery for these key service users. This study has enabled substantial insight into applying a new method of care delivery that of community based group work with nursing facilitation to support learning and adaption within a social learning framework.

This study has provided new evidence that health behaviour change for those identified as VHIU can be achieved among this under researched cohort of VHIU through group intervention and the support of social learning, facilitated by senior community nurses. This has been achieved through creation of a remarkable basic social process that requires the operation of three key interrelated factors: *comparison, learning* and *ownership*. In such contexts we hypothesise that through establishing these three inter-related factors for VHIU patient groups within a social learning context, that favourable or adaptive health behaviour change may be achieved. There is a need to now share and test this learning on a wider scale to explore its transferability further, and examine further its scope to affect policy change and adoption of a new model of intervention for community nursing to effectively and efficiently support those living with multiple LTCs in the community.

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