# Exploring conversations on the caring situation in the acute hospital setting

Elaina Smith RN, B.Sc

August 2017

Word Count	1980

## Acknowledgements

# Contents

## TABLE OF FIGURES

**TABLE OF TABLES**

| Table Number | Table Title | Page Number |
|---|---|---|
| 1 | Literature Search Overview | 11 |
| 2 | Study Settings | 28 |
| 3 | Participant Characteristics | 36 |

**ABSTRACT**

**Background**
Demographic shift and increasing numbers living with multimorbidities are seeing an increase in those receiving unpaid care support from relatives, friends and neighbours. There is a growing reliance on those providing that unpaid care support to continue to do so from Government. To that end, the Carers (Scotland) Act (2016) intention is for unpaid carers to be supported to continue to care, if they wish, without detriment to their health, and to have a life alongside caring. The Act has specific requirements for acute hospitals to identify and involve unpaid carers in discharge planning for those patients they support.

**Objective**
To investigate the experiences of those providing an unpaid care role in acute hospital setting on the conversations with healthcare staff on the caring situation in the context of the requirements of the Carers (Scotland) Act (2016).

**Methods**
Data was collected via in-depth semi structured interviews from a purposive sample of 13 participants identified from three inpatient areas of NHS Greater Glasgow and Clyde. The interview schedule explored their understanding of the term "carer" and its use, recognition of caring role, and if the caring situation was included in conversations with healthcare staff. Views and experiences of conversations with healthcare staff were examined.

**Findings**
The term "carer" was not used by staff to those providing an unpaid caring role. Participants recognised the term with all meeting the definition of carer as set out in Carers (Scotland) Act. Only three associated themselves with the term. Conversations between those in unpaid care roles and healthcare staff focused on condition information and progress updates as driven by the carers. From experiences shared, it was not evident conversations with staff met the requirements of the Carers (Scotland) Act as envisaged. There were mixed expectations on whether the caring situation should be discussed. None of the participants acknowledged any support they required in order to manage their caring role. The relationship dynamic between the carer and cared for had an impact on what support was likely to be accepted, if any.

**Conclusions**
The multifaceted nature of the dynamics associated with attempting to achieve the aims of the Carers (Scotland) Act as set out for acute hospitals, means there are substantial challenges ahead which may not be able to be addressed without significant culture change in this environment based on what found in this study and supporting literature.

**Keywords**
Unpaid carers, communication, acute hospital, legislation

## 1. INTRODUCTION

Demographic shift and the rise in numbers living with multiple morbidities are two factors having an impact on delivery of health and social care services in Scotland and across the UK (Scottish Government, 2013). The resultant growth in those with complex care and support needs has not only seen increased demand on health and social care services but also a rise in the numbers informally supported by family and friends. The latest Health and Care Experience Survey (Scottish Government, 2017) indicate many being supported with everyday living are receiving this support from out with that of formal services. They suggest the 43% of respondents in this position are being supported by family and friends. It also found 15% of respondents look after or provide support to others.

Often described as unpaid or informal carers, there are an estimated 759, 000 adult carers and 29, 000 young carers in Scotland (Scottish Government 2015). In NHS Greater Glasgow and Clyde the Census data suggests, 10% of residents identify themselves as having caring responsibilities (National Records for Scotland, 2011). The nature of caring is somewhat unknown due to acknowledged difficulties in carer recognition impacting on data collection (Scottish Government, 2015). The history behind these difficulties with recognition may have their roots in how the term has developed within social culture (Molyneaux et al., 2011).

Much of the upcoming policy and service provision is reliant on informal carers continuing to provide that role. This is not surprising when the economic value of the contribution made by carers in the UK is now estimated at £132 billion per year, similar to total health spending in the UK (Buckner, 2015). Preventing the breakdown in the informal caring situation has been the overarching aim of the Scottish Government in its policy provision over the last decade. First through implementation of Caring Together: The Carers Strategy for Scotland 2010 – 2015 (Scottish Government, 2010) and now with the Carers (Scotland) Act (2016). Implementation of the Act is currently scheduled for April 2018

The intention of the Act is to ensure carers, including young carers, are recognised, and provided with support to allow them to continue to care, if they wish to do so. They should have support for their own health and wellbeing and are enabled to have a life alongside their caring role. In order for this to be achieved, early identification of unpaid carers is seen as key to building carer's capacity and preventing any adverse impacts of caring where possible. For young carers, the aim is for a childhood similar to their non-carer peers (Carers (Scotland) Act, 2016, Carers UK, 2016a).

This all sits within the wider context of Scottish Government Public Services Reform to tackle inequalities and support communities to be fair and stronger though the responsibility for implementation of the Act is within health and social care (Carers (Scotland) Act, 2016).

Carers can come into contact with health services long before social services or other forms of support. There is recognition that hospital staff are in a key position to identify carers and utilise this healthcare interaction to inform them of their rights and the support available (Scottish Parliament 2015). Workforce development has been supported with this through the national Equal Partners in Care Core Principles approach to provide better outcomes for all those involved in the caring relationship for both health and social care settings (NHS Education Scotland, 2013). They were designed to ensure staff were able to consider multiple factors which can impact on the ability of a carer to fulfil their role from identification to empowering them to manage their caring role.

NHS Greater Glasgow and Clyde Carers Pathway process (Figure 1) was developed and implemented to fulfil the requirements of Caring Together: The Carers Strategy for Scotland 2010 – 2015 (Scottish Government, 2010). This has historically focused on areas of known need for engagement with carers such as older peoples services, stroke and long term conditions. This has involved workforce development within these clinical specialities alongside awareness raising of this partnership approach. It has been threaded through several other

NHS Greater Glasgow and Clyde board wide policies which incorporate carers including Dementia Strategy, Person Centred Care and Excellence in Care, all of which are linked to the board quality in care objectives (NHS Greater Glasgow and Clyde, 2016).

**Figure 1** NHS Greater Glasgow and Clyde Carers Pathway
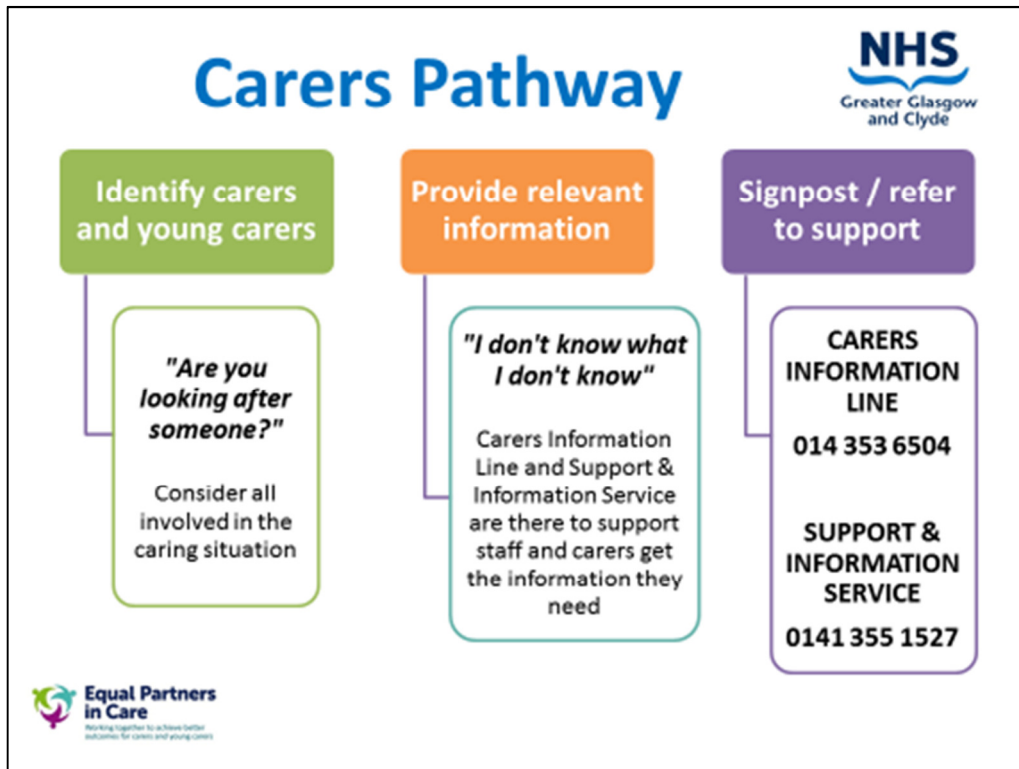


The specific duties now inferred on hospitals are intended to fully involve all identified unpaid carers in discharge as a requirement of the Carers (Scotland) Act (2016).   It will be applicable across all areas where patients are discharged from.  They include where a patient requires support post discharge that the carer is informed of the discharge, involved in the discharge planning with their views and opinions taken into account where reasonable and practicable.  This now provides very clear directives from government on the expectations of interactions in the acute hospital setting with those providing unpaid support.

The main unknown within the current process is whether conversations between staff patients and relatives take place and are effective.  This study aims to evaluate current practice in areas where NHS Greater Glasgow and Clyde Carers Pathway is established to investigate this.   By exploring the conversations as experiences by relatives / friends in an acute hospital setting to determine if they meet the requirements as envisaged by the Carers (Scotland) Act.  This will help inform NHS Greater Glasgow and Clyde Carers Task Group on elements of good practice and any areas for development along with potential barriers.

## 2. LITERATURE REVIEW

### 2.1 Literature Search

A structured literature search strategy was developed to establish what is currently known about conversations on caring in the acute hospital setting.

Few results were initially obtained when using the term "unpaid carer". Investigation found there to be an issue with this. Although used widely within policy context of UK, derivations of "caregiver" are more commonly applied in research fields and elsewhere in the world. Modification of the search strategy was undertaken to ensure inclusion of all forms of the term.

Table 1 provides an overview of the search strategy including databases searched, terms used, hits returned and the total number of relevant studies after removal of duplicates. Inclusion criteria were any reference to unpaid care or derivatives, hospital environment and interaction with healthcare staff in title or abstract published in English between 2000 and 2016. Excluded were studies where the cultural context was not equitable to that of the UK, therefor not suitable for comparison purposes. Relevant studies reference lists were also screened for any studies suitable for inclusion.

**Table 1** Literature Search Overview

| Search Terms | Database | Hits | Considered for literature review |
|---|---|---|---|
| Unpaid care* AND hospital | Web of Science | 95 | 8 |
|  | PubMed | 28 | 4 |
| Family care* AND hospital | Web of Science | 1228 | 85 |
|  | PubMed | 1324 | 96 |
| Informal care* AND hospital | Web of Science | 712 | 24 |
|  | PubMed | 642 | 20 |
|  | Total | 4029 | 237 |

With much of the drive for this topic coming from policy, the search also included policy documents and grey research relating to carers from Scottish Government, NHS Scotland, national carer organisations and other agencies.

Reference management software was utilised to find duplicates and aid in coding of articles. Relevant literature was reviewed using Critical Appraisal Skills Checklist (CASP, 2017). Coding was assigned for identifying themes for discussion in the literature review.

## 2.2 Literature Review

Most of the literature found is from a community setting covering both health and social care perspectives with some reference to hospitals exploring a myriad of views on the topic. Williams et al. (2015) commentary contends this is due to the community setting leading the support of caregivers as most management for patients occurs in this setting while the episodic short term focus of the acute setting relegates carers to a support role if they are recognised.

There has been an increased interest within the acute setting during the last five years but this has tended to be polarised to specific specialities. The dominant fields are older people including dementia, palliative care and stroke. However, there is a growing interest within critical care research linking with post intensive care syndrome.

The majority of studies focus on the negative aspects associated with caring with many studies exploring burden and challenge. This may be an indicator of how the subject is viewed within health and social care but should make us question if this is the view of wider society. Although out with the scope of this study it will be considered during review of the literature.

### 2.2.1 Definition of carer

It is now acknowledged not only from campaigners such as Carers UK but also by Scottish and UK government, that recognising the caring role is key in mitigating the negative impacts related to being a carer (Carers UK, 2015, Scottish Parliament, 2015).. This may be something which policy makers have taken cognisance of but there remains some disconnect both with those in the caring

role and the services expected to identify and support them in what constitutes a carer.

The term "carer" could be considered both a barrier and a facilitator. This was certainly the case for the researcher in undertaking the literature search with modifications required to terms used to uncover relevant studies due to multiple definitions and derivations of the term.

One of the main aims of the Carers (Scotland) Act (2016) is to broaden the definition of carer to ensure that no person providing that role was disadvantaged. To that end, the Act defines a carer as an individual who provides or intends to provide support. The previous definition as set out within the Carers Information Strategy was more akin to a list of criteria attributable to the role (Scottish Government, 2010). Carers were individuals who provide unpaid practical, physical and emotional support to a relative, friend, neighbour who are ill, have a disability, mental illness or substance misuse. While this may provide a clear description of the role, the reality of what carers experienced as viewed by their campaigning organisations, was a definition which limited their access to support when applied by local authorities. This was further compounded when the "regular and substantial" rule, limiting access unless caring for more than 30 hours or high risk of crisis, was applied (National Carers Organisations, 2015). Ultimately with either of these definitions there remains a requirement for the individual to acknowledge the support role they are providing and recognition they are a carer.

This variation in how carers are defined was also found within research studies. A number were very specific down to number of hours caring and tasks undertaken, with other stipulating minimum number of visits (Camden et al., 2011, Whittamore et al., 2014). This may have aided in clarity of their study sample but there was no reference to either why those not meeting the criteria were excluded or what impact on their finding for those hidden from their selection in these studies thus impacting on usefulness of findings. Molyneaux et

al., (2011) in their critique of the term carer, provide a measured argument it should no longer be used as it is ineffective, disempowering and implies burden. They suggest shifting the focus to the relationship from which the caring situation has arisen from as a more productive way to increase support for all involved, a view supported in the findings of Seddon and Robinson, (2015).

Seddon and Robinson, (2015) considered previous suggestions on the differentiation between caring and caregiving which was included in the guidance of the 1995 Carers Act for England and Wales in their study of social care managers and their assessment of carer needs. Determining if there was any difference given between the two components was no longer evident in practice from their findings. This distinction between caring for, suggesting actions involved, as opposed to caring about which aligns to the emotional aspects of the relationship, does broaden the scope of what requires to be addressed when assessing carers needs. They contend overlooking both components can impact on the relationship between the carer and cared for plus that with staff if there is insistence on differentiating who is carer and who is cared for. There is some weight in this finding as the study was of sufficient power, is within a UK community context and this would also apply within an acute setting.

### 2.2.2 Recognition of caring role

Within the literature there is agreement that for many, the role they provide in supporting a relative or friend is "just something they do". A number of studies attempt to explain some of the issues relating to recognition of the role of carer including the automatic nature associated with assuming the role (Knowles et al., 2016, Hughes et al., 2013, O'connor, 2007, Milligan and Morbey, 2016, Carduff et al., 2014). Common to all are the negative associations with the term which impact on the personal identity of the carer leading to reluctance to accept the term and recognition of the role though most studies are limited by the purposive nature of their samples.

Milligan and Morbey, (2016) provide an interesting view when considering who become carers. They assert that the normative assumption of women being the dominant group of primary care-givers is down to societal structures around employment legislation and social support. They found that older male carers sought professionalising of caregiving as a means to legitimise the role they provided. This links with the campaigning by UK carers organisations arguing carers be given parity with paid care workers (Carers UK 2015b). However their study was limited to white British heterosexual males with sufficient literacy levels for them to self-select for the study. While their findings are may be biased due to the sample, it does highlight the impact of normative assumptions in relation to caring which requires consideration.

Being prepared for caregiving is asserted to negate against the negative consequences of caring for many within the grey literature and the rationale given for promoting identification of carers (Carers UK, 2015a, Scottish Government, 2015). It is worth noting that while some of the data associated with this is insightful, it is largely based on convenience samples and comparative analysis which does not control for confounding variables. There are however a number of themes which have emerged linking with preparedness.

Recognition of role was found to be linked to preparedness for the caring situation by some studies. Khabarov et al., (2015), and Plank et al., (2012) both found individuals transitioning to recognising their role as carer required a level of understanding of what expected of them for this to be successful though often poorly accepted. Neither study was from the UK though both were within hospital settings. Another commonality between these studies was identification of the pivotal role played by the healthcare professional in facilitating that preparation. The differing systems in which the studies were carried out means there is no commonality in which staff group are best placed for this facilitating role.

There does appear to be a differing culture in recognising carers and their involvement from some specialities which is not necessarily directly linked with the carer role but more in the support required as part of the treatment plan for the patient.  Palliative Care, particularly that of end of life care, has a large dominance in the literature. Most are focused on management of end of life and the supports required. There appears to be an acceptance from patients, relatives and staff of the caring situation as a single unit to be considered (Henriksson and Arestedt, 2013, Moore et al., 2006, Morris et al., 2015)

A number of studies suggest there is a process which individuals go through when recognising the caring role. (O'Connor, 2007) found that how others interacted with those in the caring role had an impact on recognition.  It moved them from viewing the role as an extension of familial duties to recognition as caregiver.  However, participants in this Canadian study were from family support groups which limits the validity of the findings.   Carduff et al., (2014) in their UK triangulation study did have similar findings on the impact acknowledgement of others had on recognition of caring role.  Again this was linked with relationships but was also in the context of advanced illness in a community setting so difficult to determine applicability to the acute hospital setting.

**2.2.3 Relationships and their part in caring**

Relationships between carer and cared-for were considered in a number of studies as highlighted above in association with recognition of caring role. Gibbons et al., (2014) integrative literature review adds to this by considering from a wider viewpoint.  They contend there is transition process which many go through to recognised family caregiver similar to a rite of passage.  Although only a small number of papers reviewed were from the UK, the themes found in all papers included supported their assertion of the phasic nature involving the concept of liminality for many carers.  Describing this liminality in terms of role ambiguity, social changes and uncertainty all of which are aligned with losing identity, creating a limbo which can often be negatively associated with

recognising becoming a carer. All of these factors were linked with the state of the relationship between carer and cared for with both positive and negative aspects in establishing the new normal for that relationship.

There is also a growing interest in critical care research. Most is associated with studies on the role of family relationships in post intensive care syndrome, the persistent physical, psychological, cognitive and social problems causing significant burden to both patient and family (Davidson et al., 2012, Haines et al., 2015, Griffiths et al., 2013, Mcpeake et al., 2016). Both the literature review and systematic reviews recognised the limitations of the studies available within them but their suggestions for further study remained on negative impacts associated with caring rather than any positive factors they found (Davidson et al., 2012, Haines et al., 2015).

Davidson et al. (2012) had described a potential association between the suddenness of the life changing event on relatives' ability to transition to the care giving role. They had also suggested strategies based on involvement and communication may assist with this. It is linked with needing to be delivered at the relatives preferred level in order to minimise stress. This is a factor which is transferrable to the ward environment though only a small number of studies included in the review were from the UK so caution should be applied.

The changes in interpersonal relationships are often viewed as inevitable as the transition develops within the caring situation. Many consider this from the burden perspective (Aasbo et al., 2016, Carduff et al., 2014, Hughes et al., 2013, Knowles et al., 2016, Popejoy, 2011, Davidson et al., 2012). For some this is a gradual process which is often unrecognised (Carduff et al., 2014). The sudden nature of life changing events results in the immediate assumption of the role for others (Davidson et al., 2012). This change in dynamic may or may not be acknowledged by either the person being supported or the supporters. They may even be at different stages of recognition (Aasbo et al., 2016, Knowles et al., 2016).

Aasbo et al., (2016) study has approached this from a sociological perspective, providing a number assertions on relationships and caring adding to the complexity of this area.  They have badged this in a concept of the "biographical we", what couples do to re-establish continuity in their relationship when interrupted by illness and caring.  This is a limited sample of ten spousal carers of chronic obstructive pulmonary disease patients, however this qualitative study provides compelling insight which is found in parts in the other studies cited above.  While they cite there is an invisibility associated with caring in chronic illness they assert this is due to partners absorbing this into their relationship to maintain normality. When this was seen in positive terms there was reduced strain within the relationship. Conflicts arose when there were clashes with maintaining independence and safety often resulting in carer stress, particularly when the cared for did not recognise the risk.  This study may not be directly applicable within an acute hospital environment but this is providing context to relationship dynamics which occur in all environments in relation to chronic illness.

An additional insight was also found in this study relevant to why offers of help are declined – the unintended consequence found when help is accepted. While the intervention was intended to support families the adjustments required to accommodate was found to be too much of a disruption to be of benefit resulting in declining the service.  Again caution is required when considering this due to the limitations within the study but this could provide a rationale to be explored when considering why support is declined.

The role of the cared for in recognising the impact their illness has on the relationship dynamic is an area not found to be considered in any studies within the hospital setting though this was considered in chronic illness.    The limiting of what is shared on health and psychosocial needs by some cared for individuals with their carers has been identified as a factor impacting on the carers ability to support the cared for effectively and their relationship. This has been cited in a

number of studies from varied clinical conditions (Aasbo et al., 2016, Popejoy, 2011, Knowles et al., 2016, Hughes et al., 2013). All of these are qualitative studies limited due to their scope and sample size, though all are investigating from a long term condition perspective with similar findings which would suggest relevance when looking at management of long term conditions. This may also have links with the issue of patient confidentiality which was not overtly referred to within any of these studies.

Duty and responsibility also appeared in the literature (Al-Janabi et al., 2008) (Hughes et al., 2013, Knowles et al., 2016). Hughes et al., (2013) and Knowles et al., (2016) both explored the association between what was seen as stereotypical duties of familial role and caring responsibilities. Where these became blurred and expectation was leaning to assumption of the caring role rather than wanting to provide it was found to be a trigger for tension in relationships. This is a valid point to consider when looking at the expectations of the requirements of the Carers (Scotland) Act in involving carers with discharge planning.

Meta-ethnography was used in the development of the Carer Experience Scale quality of life indicator with duty as one of the measurable attributes (Al-Janabi et al., 2008). This study considered duty from the viewpoint of fulfilment in making caring rewarding. However they did find problems with the use of the word as many did not view it in the positive as set out. As this is the first reported use of this method for the development of this tool, caution must be applied in interpreting these findings. It does however raise the issue of the use of language in the caring context.

### 2.2.4 Communication

Effective communication is often cited as essential within healthcare. Clissett et al (2013) provides an interesting perspective to several aspects in relation to this in their study of the experiences of family carers of older people. The methods used within their study may have biased responses so require caution. The use of mainly negatively leaning prompts was described. Lack of insight relating to

care role by staff was cited as leading to poor communication and also lack of trust in some cases. Other respondents took the view the system was more at fault leading them to adopting a proactive approach to keep informed.

Lack of time is frequently cited within the literature to explain why both staff and carers avoid exploring the caring situation (Walker and Dewar, 2001). A Swedish study provided additional strands to this. It found staff avoided discussions due to time and resource limitations meaning referral to other services was the only intervention, something they did not always see as preferable hence avoided (Gusdal et al., 2016). While the system in which the study was conducted is not comparable to this study setting, it does provide a possible explanation as to why the caring situation is not evident from participants.

Bail and Grealish, (2016) looked at this same aspect but from a theoretical development of a quality indicator. They propose that the rationing of care found when time pressured leads to hospital acquired complications which they frame in a context of "Failure to Maintain". This study found that communication and health teaching was omitted in up to 80% of cases with time versus effort and value associated with this. Those seen as psychosocial issues, such as caring, were often lowest priority. This is just a theoretical concept relating only to nursing but the paper does provide sufficient evidence to consider if this is a factor in effective communication in the acute hospital setting.

Much is made about the timeous nature of when information is given and how it can impact on outcomes (Tod et al., 2016, Carers UK, 2016a). Tod et al., study provides evidence to support an "impact gap" concept relating to if information had been given at diagnosis outcomes would have improved. It fails to acknowledge potential recall bias and links failures to lack of ongoing co-ordination for patients and their carers. This may be relevant but does call into question whether we are creating a dependency culture when advocating this approach. This study was also limited to Parkinson's Disease.

Carers unfamiliarity with the acute environment manifested itself in carers being passive with communication in Khabarov et al. (2015) study. This Canadian qualitative study found this was partly due to confusion over who to communicate with. This was also reported by Bloomer et al. (2014), Coleman and Roman (2015), Walker and Dewar (2001), Clissett et al. (2013). Not knowing the routine, who to approach, when to approach was found by all these authors. While all gave slightly different potential solutions all were linked to better engagement between carers and healthcare staff. The impact of having to juggle hospital visiting and life on ability to be proactive with staff to keep in touch with what is going on was identified but not explored by (Clissett et al., 2013).

A number of papers provide interesting viewpoints on the language used to describe engagement with relatives/friends which may provide insight into common communication issues (Bull et al., 2000, Huby et al., 2007). Lack of clarity in what is meant by "involvement", "participation" "informed" is seen by Huby et al. (2007) as one potential reason for disparity in the evidence relating to engagement though not expanded.

Carers report proactive engagement by healthcare staff when the patient was unable to take part in interaction with staff due to severity of condition. This diminishes once the person was able to engage themselves (Bull et al., 2000, Bauer et al., 2011). Neither paper is from a UK context nor is indication given to the duration of the inpatient episode which could also be a factor.

### 2.2.5 Health professionals' role

Issues around role ambiguity were found in a number of studies. (Carduff et al., 2014) in their triangulation study, found there was acknowledgement from healthcare professionals to identify and support carers but this was conflicted with differing needs between patient and carer. Confidentiality issues were also cited. They also found in a focus group with staff suggestions that carers may not see it as a GP role. This was not followed through in the focus groups with

carers so of limited validity.  It does raise the question of who are healthcare staff accountable for.   They assert that this ambiguity necessitates the legitimisation of the needs of carers to provide clarity for both professionals and carers.

This leads us to question, who are staff accountable for?  The roles of staff in the acute environment which are framed within the professional framework in which they deliver their role (General Medical Council, 2013, Nursing and Midwifery Council, 2015).  Most interpret this from the perspective of the patient.

Within the field of dementia care there is a growing call for healthcare staff to provide a supportive relationship for not just the patient but also their carer which is supported in the literature (Bloomer et al., 2014, Bronson and Toye, 2015). The main driver for this relates to the advocacy role which many dementia carers provide.  These studies are very specific considering aspects of incapacity which may be valid in some cases but not all.

Advocacy was also identified by Popejoy, (2011) in relation to reconciling differences on discharge plans within family caring situations.   The health professionals reported families' expectations of them to facilitate the discharge plan that was more accepting to family than possibly the patient.  They reported concern from staff but this line of enquiry was not covered further in this US study.   There was also no indication on the numbers involved though total number of family participants was 12.  While caution is required in this study, variations of similar concerns were found in a number of other studies.

Seddon and Robinson, (2015)  found in their interviews with over 300 care managers in England and Wales community settings, tensions in managing carer assessments. Carer willingness was taken for granted and there was ambivalence by staff towards separate assessment of carer needs, particularly the emotional and relational components.  This is of particular interest due to the context in which the research was undertaken of the case managers advocating for both

carer and cared for.  Even though this study is not within an acute hospital setting, there are a number of similarities applicable to ward based staff in terms of advocating for the patients support needs in line with the Carers (Scotland) Act duties.

Bronson and Toye, (2015) raised some questions on staff behaviours and assumptions which may impact on effectiveness of contact with families.  There are problems with how transferable this is due to small sample and attrition rate but it does provide insight into issues which could apply within this study setting. Reports of staff inaction to follow protocol due to assuming the carer "seemed well informed" may be a reason why discussions on caring role are difficult to evidence.  Techniques which ensure staff can establish if information given has been understood are well used within some clinical settings such as giving cancer diagnosis, but these are not commonly used within the ward environment (Scottish Health Council, 2014).  Recall bias may remain the main reason for participants' responses but consideration must be given to the possibility that staff assumptions may have attributed to lack of exploration of the topic.

References to staff attitudes and behaviours was highlighted in a number of other studies.  Bélanger et al., (2016) review found a number of factors which had both positive and negative impacts relating to power and control.  They also reported a staff dilemma relating to acknowledgement that family caregiver input was good for the patient but this was found to be time consuming and the relatives were demanding.  Although this review consisted of 11 articles all relating to hospitalised older people, only 2 were from the UK with the majority from Scandinavia.

Power and control was also highlighted by Arksey et al., (2006) literature review considering the role of staff in facilitating choice for carers.  While the focus of this review related to social care, it did highlight the approach taken by staff may constrain choice through only offering what is available once they establish what carers are willing to do.

Popejoy, (2011) found that complexity was increased for carers in discharge planning for older adults due to the differing perspectives of those involved. The impact on decision making increased when the numbers of people increased.

Equipping staff with the knowledge and skills to effectively support carers was lacking within the literature. Only one study made any reference to the role of staff training in relation to carer interaction. Bronson and Toye, (2015) recognised the need to keep staff updated on what was required from them for the implementation of an intervention to support carers to be effective. The high attrition rate does limit the power of what was already a small scale study but this in itself highlights an issue with engaging staff in providing feedback on how they view the usefulness of the newly implemented intervention for carers.

**Summary**

The review of the current literature relating to unpaid carers is predominately within the community setting mainly focusing on the negative factors associated with the caring role. Those studies which are within the acute hospital setting are mostly small scale qualitative with narrow condition specific focus again on the negative aspects of the subject.

What they give is a picture of the multifaceted nature associated with caring. However it does not provide an indication of whether the aims of the Carers (Scotland) Act to provide supportive inclusive conversations in an acute hospital setting are achievable. An exploration of the facilitators and barriers associated with this are required to establish what required to meet this goal.

**3. AIM**

To investigate the experiences of those relatives / friends providing an unpaid care role  in an acute hospital setting and conversations with healthcare staff on the caring situation in the context of the requirements of the Carers (Scotland) Act (2016).

**Objectives**

- To examine the conversations held between healthcare staff and relatives / friends providing an unpaid caring role
- Explore if relatives/friends recognise the term carer and the caring role
- Explore what part recognition of the caring role plays in the conversations between relatives/friends and healthcare professionals
- Determine if the caring situation is included in conversations between relatives/friends and healthcare professionals

## 4. METHODS

### 4.1 Study design

The aim of the study was to attain an in-depth understanding of the experiences of those providing an unpaid caring role to inpatients in an acute hospital setting. For this to be achieved an observational cross-sectional descriptive design using qualitative methods was chosen. This design has been described as best suited to capturing the reality of the natural situation (Davies and Hughes, 2014, Green and Thorogood, 2014, Bowling, 2014).

Both quantitative and qualitative methods were considered on suitability to meet the study objectives. Existing data collection systems within NHS Greater Glasgow and Clyde Acute Services were explored. Secondary quantitative data able to answer the aims of the study were not in sufficient numbers to provide any generalisability or statistical power. This also highlighted a gap in systematic data capture on the topic which may be required to evidence compliance with the requirements of the Carers (Scotland) Act (2016).

Primary quantitative data collection via survey and data capture from case records were deliberated. Survey method is a common tool found in the grey literature on the topic such as the National Carers Organisations annual survey (Carers UK, 2016) and in some studies (Henriksson and Arestedt, 2013, Mcpeake et al., 2016, Perry and Middleton, 2011). With concerns over questionnaire design adequately capturing the complexity of the topic along with numbers and response rate required to ensure sufficient power, this method was discounted (Milligan and Morbey, 2016).

While quantitative methods would provide a generalisability to the situation they do not assist in gaining an understanding of the impact of conversations between healthcare staff and relatives/friends (Chapman et al., 2015, Davies and Hughes, 2014). The acquisition of this understanding was central to the aims of the study and key for improving the outcome of discussing the caring situation for both hospital users and staff.

Qualitative methods allow for objectively studying the realities and logic of conversation (Bowling, 2014, Silverman, 2013). This is crucial to understanding current practice and where this assists in achieving the aims of the Carers (Scotland) Act (2016). The interpretivism offered by this method allows the researcher to consider the multiple perspectives in terms of the meaning people bring to them (Davies and Hughes, 2014, Silverman, 2013). This is supported by the dominance of the approach found in the literature search on the topic.

Focus groups were discounted for a number of reasons. Although useful for enabling exploration of the topic from a range of perspectives, the potential sensitive nature of the caring role may provoke anxiety within the group particularly as this is not a naturally occurring group (Green and Thorogood, 2014). They also posed a logistical challenge in the acute hospital setting where the open visiting hours limited the availability of sufficient participants at a given time.

Semi structured interviews were used in the study. This method allowed for guiding questions to explore the complexities of the topic in a flexible way with the aim to uncover the participant's lived experience (Taylor and Francis, 2013). This was particularly important to ensure the participant's experiences were examined on their understanding of the role they were providing to the patient and their interaction with healthcare professionals. By adopting a conversational approach this encouraged participants to speak openly as well as build rapport between researcher and participant (Silverman, 2013).

### 4.2 Study Setting

NHS Greater Glasgow and Clyde Acute Services are based over 9 hospitals sites. Initial discussion with NHS Greater Glasgow and Clyde Acute Carers Working Group identified two clinical areas from two hospital sites for participation. Both had undertaken workforce development on carer awareness and had a patient population with varying support needs. Table 2 provides an overview of the participating areas.

**Table 2   Study Settings**

| Clinical Area | Speciality | Beds | Staff compliment per shift | Patient average length of stay |
|---|---|---|---|---|
| **Ward A** | Older Adult Rehabilitation | 20 | 2 RN : 2 HCA | Approx. 4 weeks |
| **Ward B** | Acute Stroke and rehabilitation | 17 | 4 RN : 2 HCA | 2 days to months |
| **Ward C** | Burns trauma | 13 | 3 RN : 2 HCA | Approx. 1 week |
| **Ward D** | Plastic Surgery | 10 | 3 RN : 1 HCA | Approx. 1 week |

RN Registered Nurse     HCA Health Care Assistant

Changes were required to the study setting after initial participant recruitment was suspended for three months due to winter pressures in clinical areas.  On re-commencement of recruitment, it was found Ward A was not in a position to support the study.  Significant staff shortages and limitations on visiting due to infection control issues had resulted in disruption to visiting severely limiting the researcher's ability to recruit any participants.

Wards C and D from the Regional Burns and Plastic Surgery service was subsequently included in the study as it was anticipated Ward B may not be able to provide enough participants within the given timeframe.

### 4.3 Participant Recruitment

Contact was made by the researcher with the study areas.  Potential participants meeting the inclusion criteria were identified in discussion between the ward Senior Charge Nurse or deputy and the researcher.  Inclusion criteria were: 1) participants provided an unpaid care support role and 2) had interacted with healthcare staff in a NHS Greater Glasgow and Clyde acute hospital inpatient setting.

Invitation letters (Appendix 1) and participant information sheets (Appendix 2) providing full details of what was involved if taking part in the study were distributed by ward staff. This also included aims of the study, information on confidentiality, participation being voluntary and being able to withdraw from the study at any point along with the researcher's contact details and how to opt-in to the study.

Recruitment was put on hold after three weeks due to prioritisation within the clinical areas from winter pressures. This allowed the researcher to reflect on some of the issues identified on uptake prior to the process being halted. Distribution of approximately 30 invitations by ward staff, had yielded no participants. Ward staff reported, while there was some interest from those given the invitations, making contact and identifying time to participate was the common reason given for not progressing.

After discussions with NHS Greater Glasgow and Clyde Acute Carers Working Group and study supervisor, recruitment was suspended for three months. It was decided to alter some aspects of the recruitment process. On re-commencement, discussion with ward teams continued as primary method of identifying potential participants to ensure no inappropriate approaches. Distribution of invitations was undertaken by the researcher during ward visiting times in line with NHS Greater Glasgow and Clyde existing engagement process for obtaining feedback in clinical areas. This allowed for the researcher to answer any questions at the time of approach including emphasising the neutrality of the study.

Where possible, interested participants were encouraged to progress to interview rather than arrange additional time. This was seen as preferable for interested participants with thirteen going forward to interview.

**4.4 Sample**

The aim of sampling in qualitative methods is to illustrate experiences not generalise (Newell, 2011, Creswell, 2013). To elicit a broad range of responses relating to conversations on caring, purposive non-probabilistic sampling was used to identify participants. This was achieved through selecting participants meeting inclusion criteria to capture their experiences (Green and Thorogood, 2014, Creswell, 2013). Inclusion criteria were participants provided an unpaid care support role and had interacted with healthcare staff in a NHS Greater Glasgow and Clyde acute hospital inpatient setting.

It was anticipated that up to 15 participants may be required based on other small scale qualitative studies (Baker and Edwards, 2012, Silverman, 2013). This was considered realistic for achieving data saturation within the given timeframe of 2 months. Changes to the participating areas resulted in the target not being met. However, the richness of the data collected from thirteen participants found no new emergent themes. The decision was taken to stop recruitment in view of data saturation having been met.

### 4.5 Data Collection

It is recognised that the researcher is the primary instrument for collection of data in qualitative interviews (Pope and Mays, 2006, Davies and Hughes, 2014). The researcher has extensive professional knowledge on the topic from current job role as change agent for implementation of the Carers (Scotland) Act (2016) and previous experience as a nurse. This provided an additional lens of enquiry which may not have been able to be explored by a researcher unfamiliar with the topic. As the purpose of the study was to explore conversations on caring in the context of the process of The Carers Pathway, the reflexivity provided by the researcher's role is central to data collection, analysis and discussion of this study (Finlay, 2002).

With the sensitivity around the topic being discussed, the researcher attempted to mitigate for any potential impacts. A relaxed, informal and open approach throughout all contact with participants was adopted emphasising the

researcher was only interested in obtaining their views and experiences. The researcher also avoided expressions which may illicit greater disclosure.

A pilot interview was conducted with a colleague of the researcher whose relative had a recent inpatient stay in a NHS Greater Glasgow and Clyde acute hospital. This tested the interview schedule for suitability of questions, approach to be taken in delivery of questions and potential responses. It also allowed for testing of equipment and preparing the researcher for the interview process. The interviewee was encouraged to comment on the process and content of questions. With no major issues identified from this, only minor revisions were required prior to commencing participant interviews. This step was important for the researcher in developing experience and confidence in the research interview process to ensure quality data generation from the interaction (Davies and Hughes, 2014).

Interviews were conducted by the researcher in NHS Greater Glasgow and Clyde clinical areas lasting between 9 and 34 minutes. Sessions were digitally audio recorded with consent. All interviews except one, took place in a private space on the ward. One participant wished to remain in the four bedded ward area with the patient for interview. Every measure was taken before and during the interview to maintain privacy and confidentiality including pausing interview when anyone entered the room and offering to stop.

Prior to commencement of interviews the nature of the study and procedures were discussed. This included assurances of anonymity and confidentiality along with reiterating participation was voluntary and they could withdraw at any point without reason. Participants were asked to complete a consent form (Appendix 3) acknowledging their agreement to take part, comprehension of the information given and for recording of interview. They were given a copy of the consent form along with the participant information sheet. All participants agreed to recording of interviews.

The interviews used a semi structured approach employing the interview schedule (Appendix 4) as a guide. Topics being explored were informed by the literature, the researcher's professional knowledge of the established processes for carer engagement in NHS Greater Glasgow and Clyde and the usual method of establishing care and support within each of the participating clinical areas. Participants were encouraged to describe their experiences of conversations with healthcare staff.  In depth questioning explored the topics discussed, who initiated and their views on the process.   All participants were given the opportunity at the end of the interview to provide feedback on the interview experience. Participants were given the option of receiving a copy of their transcribed interview for revision.  None took up this offer.

A reflective diary was kept by the researcher to capture impressions and observations post interview and when in clinical settings including interactions between clinical teams and the researcher.   Background information was collated from each of the participating areas to determine any commonalities and differences in the approach taken to identifying the caring situation and engaging with those providing support to patients.   This added to the completeness of the body of data.

## 4.6 Data Analysis

Transcription was carried out by the researcher.  This was verbatim including words spoken in local and Scots dialect, sounds, repetitions, pauses and emotions.

Subjectivity is a frequent criticism of qualitative methods (Chapman et al., 2015, Davies and Hughes, 2014).  This was minimised through the reflective approach taken by the researcher.  The same rigor applied to the research process was given to the researcher's interpretation of the data. Any perspectives and assumptions have been declared and acknowledged to negated and minimise the impact of bias (Green and Thorogood, 2014).

The iterative process was applied within a thematic analysis approach (Colorafi and Evans, 2016). Interview transcripts were read a number of times to identify any emerging themes and annotated with initial codes and sub codes. This process was based on the researcher's interaction with the data and considered the meaning and action through asking "What is going on here?" (Charmaz, 2014). Initial codes acted as keywords to assist in the retrieval of key elements of participant responses. These were reviewed and grouped together into main themes and sub themes based around the aims of the research. Any deviant themes were scrutinised to add depth to the analysis and interpretation of the data (Pope and Mays, 2006).

**4.7 Write Up**

The analysis and themes are presented in the findings and discussion sections. Direct quotations have been used to provide contextual accuracy of statements.

**4.8 Ethical Considerations and Approval**

Ethical approval was sought prior to commencement of the study in line with NHS Research Governance Framework (Scottish Executive, 2006) and Code of Good Practice in Research (University of Glasgow, 2014). NHS West of Scotland Research Ethics Service, the governance body for the study area, advised ethical approval from them was not required as the study was viewed as service evaluation. Approval from the College of Medicine, Veterinary and Life Sciences Ethics Committee was sought and received (Appendix 5 Project Number 200150018).

Issues of informed consent, confidentiality, anonymity and risk were considered. Informed consent was obtained as previously discussed in section 4.5.

Participant anxiety was a possible risk due to the nature of the topic being covered. High levels of stress and psychological strain relating to the caring role has been identified in a number of studies (Mcpeake et al., 2016, Boltz et al., 2015, Plank et al., 2012). The purposive sampling approach undertaken was

useful to allow the researcher and clinical staff to identify any potential individuals who may fall into that category. This was aided by the researcher's extensive experience of working in the acute setting and ability to liaise with staff on identifying any potential risks and establish escalation plans where required. Carers Support Services were available on the day to provide assistance if required.  This was offered to participants at the end of the interview.  None accepted the invitation to speak to the service.

Disclosure of details relating to the clinical condition of the cared for was a possibility.  For the purposes of this study there was an interest to explore any differences in impact of caring for certain conditions or multiple conditions on the person providing the caring role.  While this required consideration, there was no requirement for any clinical information and participants were made aware of this during interviews.  They were reminded that the focus was on their interaction with healthcare staff not the clinical condition of the cared for person.

All signed forms and participant details were stored separately in a locked filing cabinet, accessible only by the researcher, within a secure NHS Greater Glasgow and Clyde building.  Digital audio recordings were transferred onto the researcher's encrypted computer and erased from the audio recorder. Interviews were transcribed by the researcher, given a unique number with all identifying details removed and stored on the researcher's encrypted computer. The reflective diary was also stored on the researcher's encrypted computer. Only the researcher had access to the encrypted computer.

Data will be stored securely as per University of Glasgow MVLS Ethics Committee Guidance on completion of study

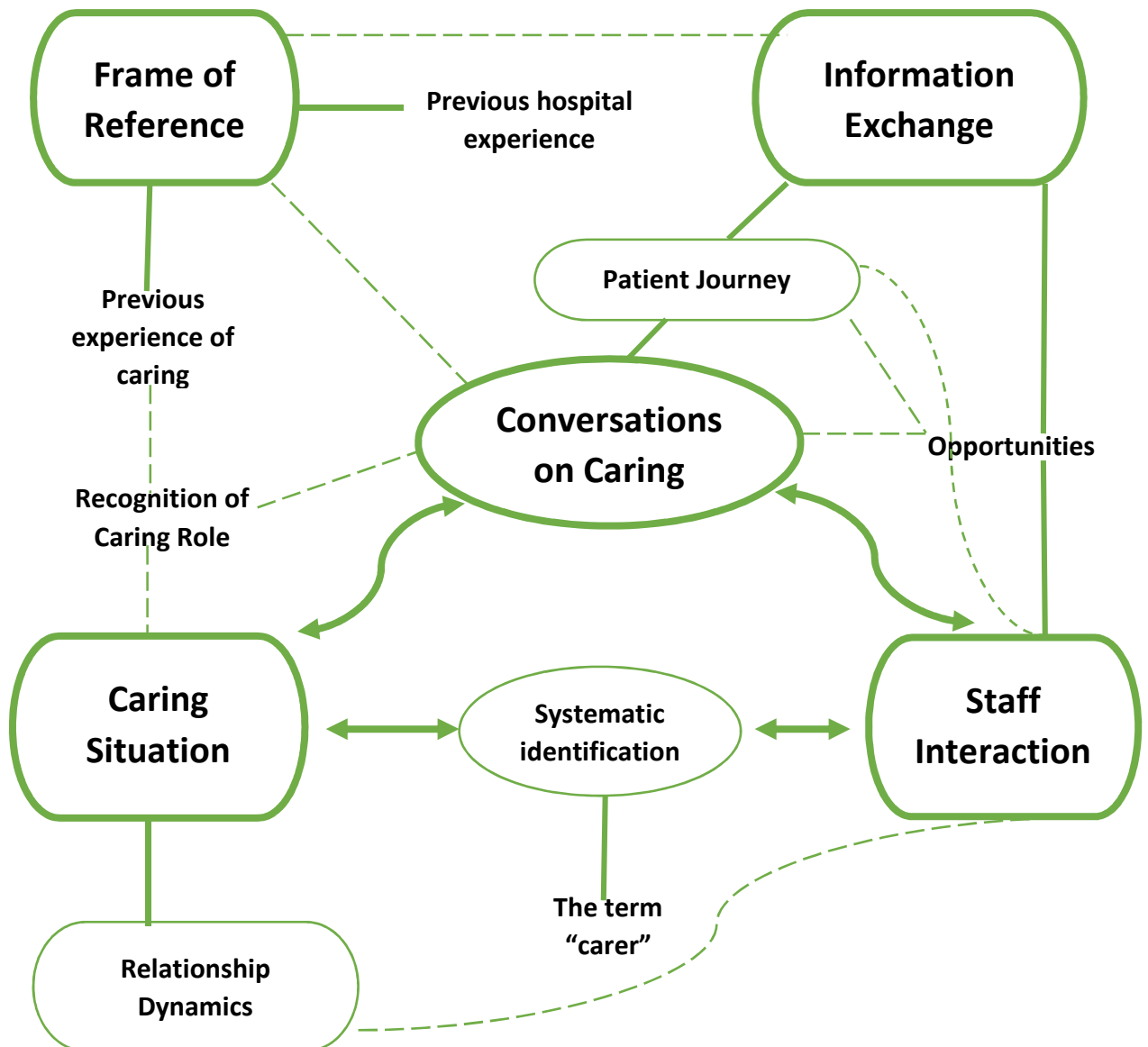**5. FINDINGS**

A total of 9 interviews were conducted with 13 participants from 3 clinical areas producing 17,563 words of transcript.  Length of interviews ranged from 8 minutes 44 seconds to 33 minutes 4 seconds with a mean duration of 17 minutes 2 seconds.

Figure 1 illustrates the themes, groupings and relationships found from data analysis.

**Figure 1:  Data themes**

**5.1 Participant Overview**

In 3 interviews the relatives wished the patient to be present. Their contributions were included in the analysis. Another interview comprised of a couple caring together for the patient. This brought the total to 13 participants. Eleven participants were white British, one Ugandan and one American. The male: female ratio was 6:6. There was an even split between those of working age and those of retirement age. Of the 9 caring situations, 4 were within the same household with the remaining 5 living separately. Two of these lived more than 200 miles from the patient. Table 3 provides an overview of participant characteristics.

**Table 3**          **Participant Characteristics**

| Interview | Participant Code | Relationship to cared for | Preadmission caring status | Living arrangements | Age Group |
|-----------|------------------|---------------------------|----------------------------|---------------------|-----------|
| 1 | P1F | Spouse | None | Together | Working age |
| 1 | P2M | Patient / cared for | None | Together | Working age |
| 2 | P3F | Sibling | Unclear | Separately | Retirement age |
| 2 | P4M | Patient / cared for | Unclear | Separately | Retirement age |
| 3 | P5M | Patient / carer | Multiple caring roles not recognised | Together | Working age |
| 4 | P6F | Partner | Multiple caring roles recognised | Together | Retirement age |
| 5 | P7F | Partner | Cared for by patient | Separately | Retirement age |
| 6 | P8M | Sibling | Establish but not recognised | Separately | Retirement age |
| 7 | P9F | Spouse | Cared for by patient, recognised | Together | Retirement age |
| 7 | P10M | Patient | Carer | Together | Retirement age |
| 8 | P11F | Daughter | Established but not recognised | Separately | Working age |
| 8 | P12M | Son-in-law | Established but not recognised | Separately | Working age |
| 9 | P13M | Son | Multiple caring roles, recognised | Separately | Working age |

Quotes used are verbatim including words spoken in local dialect, sounds, pauses and emotions.

All interviews identified situations requiring support post discharged from hospital.

**5.2 Systematic identification of caring situation**

A carer is defined as a person providing or intending to provide support as set out in the Carers (Scotland) Act. The working definition used within NHS Greater Glasgow and Clyde is of any individual who provides unpaid practical, physical and emotional support to relatives, friends, neighbours due to physical or mental illness addiction, frailty or disability.

There was a degree in uniformity found on how clinical teams established the support and care arrangements of patients in the participating clinical areas.  All report the use of the standard prompts within admission process.  At the time of the study NHS Greater Glasgow and Clyde nursing documentation asked **"Is the patient a carer? Yes / No"** or **"Unpaid care (relative/friend)"** ❑.  Posters and contact cards available in clinical areas asked **"Are you looking after someone?"** and **"Need support looking after someone?"**

The reliance on identification at admission was predominantly placed within the remit of nursing staff for collation of this information even if other disciplines had been involved.  It was also acknowledged in all participating areas there was inconsistent use of the written information collated due to the quality of what was obtained. There was also a reliance on verbal updates for all staff groups.

All participating areas (see Table 2 pg.29) described a multidisciplinary approach when discussing a caring situation with patients and relatives.  Ward B has a well-established team which includes medical, nursing and allied health professionals of physiotherapist, speech and language therapist and occupational therapist. Ward C and D were aware the system they had for linking with allied health professionals was a potential weak spot as they were only called in when required.  Obtaining feedback from them was also highlighted as a potential problem due to some notes being stored electronically and not accessible to all staff caring for the patient.  However they did endeavour to gain a verbal update when there had been a review.

Discharge planning focussed on the support needs for the patient. Documentation to support this required nursing staff to inform the relative / carer of discharge date.

The role which ward staff played in identifying potential participants was insightful. Participant recruitment required the researcher to discuss with ward staff which patients and relatives met the inclusion criteria. While the underlying principle for this approach was to prevent inappropriate approaches to potentially vulnerable individuals, this purposeful selection process by default determined who staff perceived as being in a caring situation.

Comments made by staff also demonstrated identification of potential issues relating to the caring role. Not recognising themselves as carers was cited by staff for a number of potential participants. There was a sense of concern and frustration relating to two potential participants in particular. Both, in the view of staff, were not acknowledging the impact of caring and the risk to their own health and wellbeing. Staff were unsure they would even consider participating such was the level of under recognition.

### 5.3 Conversations on caring

### 5.3.1 Opportunities for conversations

Several factors emerged when considering the opportunities for conversations on caring. All the patients were unplanned admissions to hospital. At the time of interview, length of stay for each patient ranged from 3 to 79 days with an average of 39 days, median 16 days, and total days in hospital 203. For two participants the time in hospital was viewed as a barrier to discussions with staff. The short duration of the stay and movement between clinical areas had limited the chances for one participant. It was the opposite for P8M. His need to return home potentially before the discharge of his relative was seen as an issue.

> "I mean the end of the week ehm we're hoping for the end of the week [discussions with staff] ye know which will give us the chance to get back home on Monday because we both have other things to do." P8M

Distance from hospital materialised as a common theme in five of the interviews. Three participants were relying on public transport to access hospital visiting hours, two of which were over an hour in duration each way.

"So since I don't drive, I can't come every day." P1F

"Well its 5 minute drive tae the ferry an its only 10 minute drive to here but eh I don't like boats. It's rough an it's been really fantastic touch wood [laughs] so he knows if the wind is howling an the ferry's thingying that I might not be over." P9F

Two participants did not live in the same area as their relative with both temporarily re-locating to be near the hospital. While there was an existing routine of visiting when their relative was not in hospital, both described major impacts on their life to enable them to be there for their relatives.

"We live in Yorkshire. We come up about twice a year but sadly [relative] is not a traveller. Eh we'd have come up by car but we've given up driving long distances so it's not a bad journey. We get a train from Leeds to Carlisle and eh a service up to Glasgow from Carlisle and then the local train down here. Slight problem this time in that there's a landslide just at Appleby. So that's a bus trip between Appleby and Carlisle. It didn't add very much on coz we used to be about 40 minutes wait at Carlisle for the Glasgow train and of course it took about ¾ of an hour the train usually does it in about 35 minutes because there's no stops in between . So we still caught the train we would normally have caught." P8M

"I live in Colchester. Yes, normally I try and get up and visit my dad usually about 3, 4 times a year. A bit more often more recently as he's sort of been getting less and less sort of independent. Coz obviously, because I live far away [laughs] I have to think to myself well what I'm going [pauses]. Realistically how long am I going to be up here? A mean it

doesn't bother me if I'm up here for 6 weeks or 6 years. That's just what's
going to happen."  P13M

Visiting hours were not mentioned directly though one participant did describe attending the hospital afternoon and evening.   All participating clinical areas operated a system of open visiting from 130pm to 8pm.  Staff in these areas did comment there were peak times when most relatives attended usually between 2pm to 3pm and 6pm to 8pm.

### 5.3.2 Staff interactions

Availability of staff was highlighted by a number of participants, particularly relating to the business of the clinical area.

"To be quite honest with ye I think the staff are too busy.  I don't think
there's enough of them fir the type of ward."  P9F

"Just everything seem to take time. They're quite busy [pauses] you've
just gotta go [pauses].  They're quite busy in here." P5M

There did appear to be some confusion on which staff group participants were interacting with.   Nursing was the dominant discipline with many participants naming individual members of the team.   For other staff groups, particularly allied health professionals, participants would name them but then guess their role.  The physiotherapist and occupational therapist were interchanged by three participants along with the speech and language therapist being mistaken for the dietician by another.

Accessing medical staff was described in only three of the interviews and all spoke of requiring to make appointments.  This system failed for one participant who had to re-request the meeting.

"I did actually call and leave a message with his secretary when dad was
first admitted an nobody ever got back to me.  And just between one
thing an the another ye know you don't follow it up yourself an then the
other day I just thought no I need to speak to the consultant.  I do need to
find out ye know what's been happening with that, actually what

happened to him initially because there was a little bit of confusion in my mind as to what actually had happened ehm and I just wanted some clarification."   P13M

There did not appear to be any reference to junior medical staff as all participants spoke of discussions with at least registrar or consultant grade.

Most participants only discussed the face to face interactions.   Two did reflect on telephone interactions.  It was interesting to note that one participant had chosen to use the telephone to question the care their relative had received after having attended hospital that same day.   Though there was no direct reference to telephone discussions for P1F, she did acknowledge the need for updates which were likely to be via telephone.  This related to her being unable to come to the hospital due to her partner's movement between clinical areas and the distance she required to travel to get to the hospital via public transport.

"Well, the most important thing to get is the updates just about him especially when I'm not always here to see the doctors or to talk so when you're home you want to know, what's happening, what's going to happen, how's he doing, is he getting any better or something, when's he coming home."  P1F

All these factors together suggest there is only importance given by participants to interaction which is face to face with staff.

One interview provided significant contradictions in recall of staff interactions.  P9F response when asked which staff they could recall having conversations with was

"Quite frankly none." (P9F)

This was confirmed by P10M (patient).  This was in stark contrast to the ten minute interaction observed by the researcher prior to approaching the couple to participate.   There was no reference to this interaction at all during the interview.  As the interview progressed P9F described interactions with all staff

groups available within the clinical area. The common theme to all these interactions was dissatisfaction with the information given.

> "Well I had an appointment with eh a Dr [Consultant] wan time and he told me absolutely nothing. It was like what he's tell everybody." (P9F)

> "We spoke to that chap. It was Dr [registrar] Dr [Consultant] was on holiday. And when I ask the nursing staff I don't get much information either." (P9F)

> "Well I did get [pauses] one of the physios yesterday did give me a thing yesterday to go online an there was a part for you to print off and ring and ask questions but when I printed it out it was so small I couldnae read it [laughs]. Aye this thing here [shows information from Stroke4Carers with very small print] Couldn't believe the size of the print that came out." P9F

This was not the case for the majority of participants. Most spoke in glowing terms of their interactions with staff. Again the dominant staff group was nursing.

> "I think they've been very good in here." P3F

> "Oh definitely the staff are absolutely brilliant, brilliant so they are. [Senior Charge Nurse] he's, he's a diamond. Uhu we made an appointment wi the doctor yesterday an he was brilliant an naw an we knew where we stood so we know she cannae get back home again an things like that but as a said the staff have been absolutely brilliant." P11F

> "I see the nurses as they come and go an as they give care to ma dad an to be honest the care that they've been giving is exemplary. A can't fault it in the slightest. They've been really really good with ma dad." P13M

Nursing staff also appeared to be proactive in their interactions with participants which was appreciated by most. Those who spoke of actively seeking out staff did acknowledge this was in their nature to do so but did reflect it may have had an impact on their relationship with staff.

> "Oh I do ask. I make sure I ask every question that I can think of. In fact I'm sure they get fed up with me when they see me coming. [laughs] Oh here she comes." P7F

> "But I [pauses] in my mind I need to coz I'm a wee bit of a control freak [laughs] I need to know so that I can think to myself right, is there things I need to be doing planning, maybe getting information so that in the eventuality when he does get out that I can then go bang, bang, bang I've got everything in place an a know that dad's alright. An then I'll be a happier bunny as well as him. [laughs]" P13M

### 5.3.3 Content of conversations

All interviewees described situations with elements of unpaid care ranging from emotional support through to complex regimes for wound management and delivery of personal care. However most were in the context of providing background to the researcher. These same themes did not emerge when exploring discussions with staff.

Most interviews required the researcher to ask further questions of participants for them to recall the detail of conversations with staff. Recall bias may explain some of this. However the content described by participants does suggest the nature of what is being discussed is not necessarily what they require at the time of the interaction with staff. There appears to be a disconnect in the information interchange which participants are unable to navigate to meet their needs for the situation they are in.

> "A think a lot o the conversations a like more or less just sit there OK I do contribute an that but I think the conversations within the family are still

trying tae come tae terms wi hat happened tae her. Ye know it's pretty

bad ye know." P12M

This may go some way to explaining that observed with P9F in her interactions with staff.

"To be honest I'm not really getting ma head round what's going on

[pauses] but we're getting in a routine now I can see some progress in

[patient] but I'm still wondering if this is normal." P9F

Content of these conversations for the most part, tended to focus on what happened that day.

"Ah do ask him then I go ask right what's he done, how's he been, has he

been all right, has he been working?  Is he eating or is he drinking?  Just

[pauses] well he's had diarrhoea an a just ask if it's clearing up or what."

P7F

Erh a little. [pauses] We haven't had much contact with the thingwy, staff

here. Talked to 1 or 2 of the nurses haven't seen any doctor and ehm

[pauses] we actually [pauses] we [pauses] Apart from finding out how

she's feeling. P8M

An information verification approach was in evidence.   A number of participants described first checking with the patient and then confirming with staff.  This was seen as a required method for two participants due to the condition of the patient and their inability to update them direct.  However it was acknowledged by another participant cognitive ability, while not a factor for their relative, would require this approach at certain points in the patient journey.

"Eh fortunately dad's quite cognitive so he'll tell me if, if there's anything

going on or if he's been doing anything ye know, who he's seen an what

not. But eh when he's had a couple of wee bad episodes ye know, so the

staff are the first ones to when I come in they'll grab me an they'll say oh

can we have a wee word an they'll say this happened to yer dad that an

happened to yer dad an ya think OK that's fine good to know." P13M


The primary focus described by all participants for interactions with staff was updates on the patient's condition.   Establishing progress with what had been happening that day was central to all enquiries.

"A asked them if he took a stroke.  He got an MRI which suggested that

they don't think he'd taken a stroke.  It's usually [Staff Nurse] I speak to

an eh he gives me most of the information that I need.  Yesterday

[patient] was upset [pauses] he was quite miserable but it's to do with

the medication he's on for his pain the co-codamol. [Staff Nurse] said it's

causing problems which makes him constipated and that's a big problem

for [patient]. So apart from that everything's fine"  P6F


"Well I asked what ehm if there was a time where we could expect things

an it's different for everybody an I said is this type of stroke what they

called a cerebral haemorrhage yip."  P9F


This was no different for P5M even though his situation was a level of complexity unlike the other participants.  He was the inpatient and had described providing unpaid care role to four members of his immediate and extended family.  There was recognition from him to understand his condition using reliable sources. His focus was on what he required to return to his normal life.    It did not include anything related to support he may need to manage his caring responsibilities.

"I've never really thought too far doon the road I'm just still still waiting

on the results of tests an stuff.  I don't know a lot about [pauses] I know

I've had a stroke an quite fortunate compared tae a lot of other people.

[Pauses] A don't know much about it.  I need to read up an that. Coz ma

mother in law, she's got a lot of health problems and the first thng they

dae is Google everything an it disnae help. [Laughs]  Mmm I'm just

> wondering when I can get back to work and stuff like that.  When I'll be
> able to drive again, stuff like that."  P5M

**5.3.4 Conversations on caring role**

All interviews except one described some level of support required after discharge from hospital. This was both emotional and physical.  Major adaptations to housing and lifestyle were required to accommodate the changed needs of the patient for some participants.  However these topics were not always described when relaying discussions with staff.  Many voiced concerns to the researcher but again, these did not appear in descriptions of direct interactions with staff.   During conversations with staff the focus is for the patient's needs.  The support role provided by the participants as unpaid carers or their potential support needs does not appear to be recognised or acknowledged by either participant or staff in the descriptions given during interviews.

> "No just worried about when he gets home, how things are gonnae work
> out if he's gonnae have to stay downstairs because it's upstairs and
> downstairs that we have."  P6F

There was more detail considered for P7F including insight into the difficulties being faced by her partner with rehabilitation.  This may be due to her own experience of also having rehabilitated from a stroke.   Again there is no reference to her role and potential support needs within this situation.

> "Well I'm wanting to see physio and occupational therapist is going out to
> the house Monday and I'm gonnae, I'll be out there to meet them. Coz
> one of the staff she'll be there to see the layout of [patient's] house.  Coz
> if he doesn't get this flat an he maybe has to go back to his own house til
> he gets one. An I doubt it. [Patient] is gonnae need a wheelchair.  That's
> my opinion because he's just [pauses] I don't know [pauses] I've said to
> him, I think you've given up haven't ye.  He says yeh.  It's hard I said a
> know I've been there [pauses] but whatever [pauses] [shakes head]" P7F

Only two participants spoke of having clear goals for what they needed from these staff interactions in relation to the support role. For one participant this amounted to simply informing staff of their intention to take their relative home. This same participant had been highlighted by staff during the recruitment process as potentially not recognising themselves as a carer. Staff had voiced concerns at the participant's refusal of support despite what they described as an obvious need due to the patient's deteriorating condition. The participant did describe awareness of support but was clear in her interview it was not required.

"[Occupational Therapist] approached me I think, she'd already spoke to [patient] But I had said to [patient] he'd be coming to me anyway, so she approached me to say to just say you know was this the case and I was agreeing with it. They were discussing getting a care package for him that was if he was going home to the flat. So it was just really a case of ehm him just coming home to stay with me til he's stronger. That was all."

P3F

While there was a similar tone of informing staff with P13M, there was a lot more attention given to the detail around the broad aim of getting his father home but also recognition of his role in this.

"Ehm well I think having spoken to the consultant today ehm I think that the staff are now going to be more aware of maybe how I [pauses] you know what coz not just him [pauses] it's about me it's about ma dad an ma dad's wishes an me. Dad gets what he wants – to go home. All I've said is that I understand if he needs acute medical care I don't mind him staying in the hospital. But if it's a case of they're keeping him in hospital just because it's easier to look after him, or they view it's easier to look after him, then maybe it would be better actually if we looked at a care plan that could be done at home because I think that ma dad would greatly benefit from being at home." P13M

What is common to all is there does not appear to be consideration of the potential support needs for them as unpaid carers in the discussions with staff

from these interviews.  This was very much the case for P5M.  It was not a topic he expected to be discussed when in an acute hospital environment.

[RESEARCHER] "Is that something [caring role] that you would possibly have a conversation with the staff here about?"

"Naw no that anyway eh [pauses]."  P5M

This may go some way to explaining the concern expressed by staff for this participant. He did not appear to associate his own unrecognised complex caring role to four family members and its impact on his own health and wellbeing, a factor staff contributed to his current inpatient episode.

However another participant who also did not recognise themselves in the caring role did describe succinctly what the conversations were in relation to looking after her relative.

"About looking after him, yes mmm yes when he comes out."  P3F

While both described providing support roles which they acknowledged but did not see themselves as carers, P5M was the patient and P3F the relative of the patient.

### 5.3.5 Hospital experience

Previous experience of hospital was described in four of the nine interviews.  This knowledge did appear to be utilised by two participants in their approach to conversations with staff.  P6F own previous experience of having had a stroke provided her with insight to the difficulties her partner was experiencing with rehabilitation and who to speak to on how he was progressing.

For P13M his previous experience very much informed his frame of reference in terms of what he would be looking for in his father's discharge.

"We had a very bad experience here when my mum was in and and to the point that we ended up actually taking my mum to [neighbouring hospital] rather than being here.  And they were fantastic.  In fact they

put a care package in to get my mum home so she could die at home and

it all happened in 24 hours.  I've been there, I know that it works.  I know

that when everything actually is put into place oh gosh it works so well

and they were fantastic.  They helped ma dad and me look after ma mum

in her last days and [pauses] That kind of help was just as vital as us being

there with ma mum so yeah."  P13M

## 5.4 Recognition of caring role

All interviews provided descriptions of situations with elements of unpaid care and support requirements post discharge from hospital. Multiple themes emerged from the data relating to the caring situation and recognition of the caring role.

## 5.4.1 Use of the term carer

Establishing participants' understanding of their caring role was explored by the researcher using the same questioning approach applied to patients at admission within the clinical areas. The rationale for this method was to determine if this line of questioning identified the caring situation whether asked of the patient or of a relative, a common practice when the patient is unable to complete the admission process.    When asked if they looked after their relative, most participants initially described this in general terms of their relationship rather than any specifics relating to caring.   There was some acknowledgement to support provided.

"I don't mind, coz it's my husband.  It's my job to take care of him

[laughs] so eh I don't mind."  (P1F)


"Well he looks after himself but I do I do things for him." (P3F)


For one participant, roles had been reversed due to his admission to hospital.

[Researcher: Do you help look after [patient]?]

"There was no need. He was fine. He looked after me [laughs] Well I've

got angina but P10M did the shopping an the hoovering an dusting."

(P9F)


Pre-existing health issues limiting their ability to provide physical components of the caring role was highlighted by another participant. She had previously been advised to give up a paid care role and accepted she would never be able to provide physical care to her partner.

When considering this alongside their responses to whether staff had referred to them as carers, only one participant confused this with paid care services. This was in reference to their relative requiring 24 hour care. None could recall being referred to as carer by staff. Only one associated this line of questioning with identifying themselves in the caring role.

"But I am his carer [pauses] not as in the whole thing but I am his carer at

home because he's my partner." (P6F)


Confidentiality was raised by one participant as a positive for establishing who staff should be speaking to.

"When you do get a question, oh is so and so your carer? So the

questions are coming from them [staff] which I think is yeh, which I think

is a positive way to go." (P2M)


When asked directly if they saw themselves as carers there was a stark contrast in responses. Only three participants acknowledged they identified with the term. All three had previous experience of caring. One as the cared for with the remaining two providing multiple caring roles. The duration of these caring relationships was not known but two of the three spoke of lengthy timeframes extending to a number of years.

**5.4.2 Previous experience of caring**

Seven of the nine interviews described support roles prior to the current inpatient episode. Three detailed complex caring situations for multiple persons, one where the participant was the inpatient.

There was little distinction in how the support provided was described depending on whether the person recognised themselves as a carer or not. For the four participants who did not see themselves as carers, all spoke of support situations which they were able to acknowledge as that, yet they did not see themselves as carers.

> "Well it was me, ma husband an ma brother. Ma other brother lives in Plymouth, an we done like shopping or washing things like that. She was a very very independent woman, very independent. She's got a pal an she phoned her every morning an a couple of times she couldnae get her so she obviously phoned me an a was going doon an getting in tae couple o times wi found her in the toilet, she was in the bedroom, an that one there she was in the bedroom. Wan time I had tae get the fire brigade tae open the door, she I think it was the mortise lock, she had the snib on an it took the fire brigade ages tae open the door." P11F

Contradictions were found when exploring experience of caring and whether they saw themselves as carers with two participants in particular. P7F was adamant she was not a carer yet she spoke of the support she would provide. She had previously been employed in the care sector and also been cared for when she herself was recovering from a stroke. It was even more intriguing when she mentioned at the end of the interview she was a member of the Scottish Government Carers Parliament and was due to attend again soon.

> "But it got too much for me [paid care job]. Doctor says you can't do it anymore. So I'd never be able to care for [patient]. I will go up [pauses] We're trying to get this flat for him [pauses] If I go up, if I go up I will do tidying up for him and ma daughter will come up [pauses] nope not a carer." P7F

Throughout P5M interview, multiple caring situations were described: a wife with fibromyalgia and anxiety, a now adult son with recent diagnosis of high functioning autism, his mother-in-law with cancer and a housebound brother. Despite describing the support he provided he did not see himself as a carer.

Researcher: Do you see yourself as providing a caring role?

"At home? [pauses]  Eh naw, no really, naw.  I know some people take on the role of carer but they just dae it as as family int it its [pauses] I even [pauses]  Ma brother's got fibromyalgia so I go doon an help him wae stuff take him tae dae his shopping an stuff like that either that or he wouldnae go oot the hoose."  P5M

For those who recognised their role, P9F was the only participant who made little reference to the caring situation prior to this inpatient episode.  This may have been due to the role reversal she was experiencing. P10M had provided the support role prior to his admission due to her angina limiting her ability with some tasks.  This was something he was no longer going to be able to fulfil due to the extent of the residual deficits from his stroke.  The focus of her reflections on support needs related to P10M, not on the tasks she had previously depended on him undertaking.

Most of these support situations were very complex.  All articulated tasks undertaken in their descriptions.  No reference was given to any provision of emotional support by any participant with previous experience of caring.

Development of these support roles appears to have been over a prolonged timeframe from the descriptions given.  This may account for the under recognition of the role in some of the participants.

### 5.4.3 Carer strain

The three participants who recognised themselves as carers had a common theme of exhibiting signs of carer strain. This can be defined as a problem which has potential or is causing stress or a threat (Robinson, 1983).  While there was

some evidence of this in those who did not recognise themselves as carers, the extent of the strain expressed openly by two participants was considerable.

> "I know [pauses] that yer all worn thin [pauses] I know sometimes yer looking [blows out her breath] a go into the kitchen an just start talking tae ma self because [laughs] he's got something an its ye know [pauses] I just go into the kitchen an talk to ma self [pauses] he's quite demanding."
> P6F

The language, tone and demeanour exhibited by P10F was suggestive of being in a highly stressed state, a sign of carer strain. She openly expressed anger and mistrust at the staff to the researcher which may have been impacting on her interactions with staff.

Despite their extensive caring roles, none of these three participants were linked to carer support services at the time of interview. There was some level of awareness of these services by two of the three participants but no interest to engage with them even though they were available in the ward at the time of the interview.

> "I have to do all that fur him anyway. I got a new shower in for him cost me ma life savings and he's been in it twice. I've gotta go in along with him an a come oot like airy Mary [laughs] otherwise he just gets washed fae top to bottom everyday. Tha's ma job an that's it, that's what happens. The party's over [laughs loudly] so it is. I'm a carer for ma son too, I get part care for him because he works now. Ma son has ehm had 2 brain operations and it's not cured it could come back again. But he's able to work an he doesn't take seizures now because he's on medication for it. He husnae had one for 8 years [pauses].But the medications not good for him [pauses] He's really terrible [pauses] ehm an he's hard work" P6F

This was not the only reference P6F made to financial concerns or additional strain during her interview but even when informed Carer Support Services could assist with this, the offer was declined.

This decline to access the Carer Support Service was true for all participants.

### 5.4.4 Resilience

There is a level of acceptance and stoicism exhibited by many of the participants to their situation.

> "I think I'll just take it as it goes [pauses] as it comes should a say." P6F

Even with the complexities of his dual caring role, with one relative in Scotland and the other 400 miles away, plus insight into the impact it could have on him, P13M reflects that he is fortunate

> "Fortunately I'm now in a position where I can work anywhere where I can get a broadband signal. So yes I'm just very fortunate. I could never have been able to look after both my husband or my dad if that had not been the case. It would've [pauses I would have probably been in a hospital with a heart monitor on me going [lots of anxious deep breaths] having panic attacks thinking what am I gonna do or else I would have just said fuck you and walked out coz there's just no way in the world I would have been able to cope. That's just not [pauses] doesn't bear thinking about [laughs]" P13M

The use of humour to temper descriptions of stress and concern came through strongly in those who recognised themselves in their caring role.

> "I'll tell you it was a comedy of errors [laughs]. And because of his stroke he couldn't have crutches because he has no, he still has no balance. He still leans to the left [laughs] So I'm kinda like aaahhhh [mock scream] What do they say…. What doesn't kill you makes you strong [laughs]."
>
> P13M

### 5.5 Relationship dynamics

Relationship dynamics came across in many of the themes. Participants were in what could be recognised as familial relationships (Table 3 pg. 38). Five were partners / spouse, two siblings and two adult children. Many of the participants spoke in terms of conforming to societal norms when describing their relationship.

> "I'm his partner, no his wife. It's the same thing isn't it? Well, many years
> 40 odd years you can say [pauses] well 37 years. We've been there an
> done it so [pauses]." P6F

Scenarios described spoke of assumptions linking to relationships and the support role being provided.

> "When somebody, when somebody you love needs help you help them.
> It's something as I said that's just in my nature." P13M

The views expressed by P2M may be reflective of his working out with the UK.

> "In Europe, I think if a woman's not seen as being a husband's carer in
> incidents like this then I think the woman would be somehow typecast
> and eh she wasn't doing her job. It's really eh that's her job to take care
> of him." P2M

Reference was made to wider family in all but two of the interviews. There was recognition from P13M that due to the nature of his relationship with his parents, this had led to him assuming responsibility of caring for his father even though he lived further away.

> "[sighs] I feel like that and I am and always will be, the primary carer.
> Ehm I have got a brother who comes in and visits and that's great but
> ultimately even though he lives a lot nearer than I do [laughs] I've still
> always had a much stronger connection with my dad, with my mum and
> dad and so yes that's why I've just [speech trails off] " P13M

Varying degrees of duty were articulated by some participants.  A sense of expectation of his support role was expressed by participant P8M purely down to the familial link.

> "We're not close.  So its not that [pauses] it's a long relationship but it's not by any means any form of close friendship.  You know … she's my sister that's what I say that's it ye know.   But eh no it's not a deep relationship but I call it a bloodman she is my sister after all."  P8M

Duty was referred to directly by P7F but only to refute it as the reason for her actions.

> "[Visits hospital] Every day an every night He's on his own so I wouldnae do that leave him on his own.  Coz when I took my stroke he was there and helped me through it. So it's not that it's a duty or anything I just feel myself that I need to consider what [speech tails off]" P7F

Complexities within the relationships to those they cared for was highlighted by a number of participants. This included living arrangements, distance, conflict and concerns for the future.  P1F and P2M spoke of the difficulties they had faced in being able to live in the same country.

> "So we got on the 5th application when we finally got married we were successful on the 5th application.  You got your approval to fly on 27th of December, 6 months approval, 6 months approval.  So eh, she got, she got her approval to come through."  P2M

For P6F, her partner's idiosyncrasies' appeared to be causing strain in their relationship.

> "He's awright when he's awright ye know but [pauses] when you're not doing it the same way the nurse did it [sighs] I said wait a wee minute, I'll put ma peeny on.  That's what he's like everything's gotta be perfect.  A think the older he gets the worse he gets.  You want tae see his wee corner, all his stuff is perfect, his hankies an everything [pauses] his socks. That's no me."  P6F

## 5.6 Language

Interesting language was used by a number of participants in describing their interactions with staff.

There was an appreciation for the directness in response described by some suggesting clarity is valued by participants.  This was not evident in all interviews.

> "As I say I ask them the question an they give me it an they don't beat about the bush.  They just tell you as it is which I prefer coz there's no sense in them giving me [pauses] I need to know what's what.  I do ask."
>
> P7F

Others inferred there was a potential gatekeeper role being undertaken by staff on the information shared with them.

> "Mmm well if you ask them they tell you what they know."  P1F

> "They're fairly good at sort of keeping me updated on anything that they feel I should be, I should know about."  P13M

When exploring what they expected from these interactions with staff this was rarely expressed openly by the participants in anything other than satisfaction with the interaction.  For the two participants who did reflect on their expectations, their responses were very different.  It should be noted that P6F was familiar with the acute hospital environment and acknowledged their role of unpaid carer.  This was not the case for P5M.

> "Dunno…… don't really expect much."  P5M

> "Everything is plain and simple, when I speak to them I get the answers that I'm probably expecting an well [pauses] sometimes take a wee bit longer or things to happen [pauses] it's the plans.  Everything takes time."
>
> P6F

Considering this factor alongside the evidence of outcomes from these discussions it is not surprising that there is little clarity in most of the interviews. Only those participants who spoke of previous experience of both unpaid care and the acute hospital environment were able to reflect on this in their interactions with staff.

## 6. DISCUSSION

In this section, findings are discussed in relation to the aims of the study. The relationship between other published studies and findings from this study will also be explored. Strength and imitations of this study will also be considered.

### 6.1 What purpose communication

A number of levels were found within this finding. Despite staff being equipped with knowledge and skills to effectively engage with patients and their families on the caring situation and a directive to do so, there is little evidence from this study which demonstrates that conversations specifically on the caring role are happening. The experiences described by participants is on the whole of positive and compassionate engagement but, there is limited recognition on the part of the participants as to what is being discussed is associated with their role in supporting the patient.

### 6.1.1 What discussed

This study found the main purpose reported by participants for interacting with staff was to receive condition information and progress updates primarily for that day. There was little reference to future planning such as support needs for either the patient or them as the carer. When the patient was getting home was a top topic for discussions with staff but little reference was made to any specifics. This is in keeping with the literature (Morrow and Nicholson, 2016, Plank et al., 2012, Yedidia and Tiedemann, 2008). Few participants in this study spoke of interactions which would suggest were in line with the intent of the Carers (Scotland) Act. Those who did were established in their caring role. They also declined the offer of linking with support services.

It was interesting to note that all participants were reflective of the support they provided openly with the researcher. Yet there was reluctance in considering speaking to healthcare staff or the carer support services available on the ward on many of the issues they covered. For one participant his caring role was not a topic he expected to be discussed. Staff had identified this as a concern due to

the risk attached to the participants own health and wellbeing. He was ignoring the medical advice given to prevent another potential life threatening event in order to continuing with his multiple caring roles. There was also a reported sense of powerlessness by staff in this situation. While risk is a well-established factor associated with carer assessment, there did not appear to be any papers from an acute hospital setting looking at this. Most of the literature related to conflict in decision making with dementia carers (Morrow and Nicholson, 2016, Stirling et al., 2012, Walker and Dewar, 2001).

There are wide variations found in the literature on communication and carers. The common theme found between them is the satisfaction with the interaction by both carers and staff. As with a lot of the literature found relating to carers, this is predominantly viewed from a negative perspective for both staff and carers. Some studies were open in asserting interaction with carers was a challenge or burden (Agard and Maindal, 2009). For carers dissatisfaction with being kept informed and involved was common (Bélanger et al., 2016, Jurgens et al., 2012, Whittamore et al., 2014). All of these were set in older people's clinical setting.

This was not the case for this study. All except one participant spoke in positive terms of their interactions with staff. Even when they described some aspects of interactions which were negative, they were doing so having rationalised why it was a negative experience. These were all attributed to the system and process failure not due to the health care staff involved. This would suggest the approach adopted by staff within this clinical setting ensured effective communication which participants were satisfied with.

### 6.1.2 Preferred level of communication

The negativity described by only one participant is an interesting anomaly. The stark disassociation found between what verbalised, (no interaction with staff), to what then subsequently described, (several in-depth interactions with exchange of information), and observed by the researcher, (a conversation with

nurses) should be better considered. Davidson et al., (2012) literature review described this type of behaviour was found within families in critical care. They proposed the sudden nature of the life changing events impacted on relatives' ability to transition into the caregiving role. Finding the preferred level of communication was central to this minimising the negative outcomes from this. If not undertaken at that preferred level by the relative, there was an increase in stress and decrease in retention of information. They also linked this to preventing negative outcomes for the patient. While the trauma of a critical care admission provides the evidence on this, the key component is the impact of stress on the person's ability to effectively engage on what required to transition to the caring role. This is of particular importance when bearing in mind the aims of the Carers (Scotland) Act (2016).

What has been more difficult to establish from the findings of this study is the impact of the interactions between staff and families on ensuring the caring situation is discussed and supports deliberated. If we consider this alongside most dissatisfaction found in the literature relates to being kept informed (Bélanger et al., 2016, Jurgens et al., 2012, Whittamore et al., 2014), this would suggest there may an association with preferred level of communication and transitioning of caring role which is being overlooked.

## 6.2 The impact of defining carers

Evidence found in this study supports the views cited by (Molyneaux et al., 2011) and (O'Connor, 2007) that the term carer is ineffective in its original intention. While staff are able to identify who carers are within the relation dynamics of their patients, they are not referring to these people as carers based on the findings of this study. Recall bias is unlikely to have impacted on participants' answers as 100% could recall staff not using the term with them yet all described providing support roles which by definition made them carers. All participants recognised they were providing a support role in some shape or form but only 3 acknowledged this as that of being a carer.

Workforce development that has been undertaken across NHS Greater Glasgow and Clyde and in the study settings may in part be responsible for the lack of staff referring to relatives as carers.  Training to support staff in identifying, involving and supporting carers does acknowledge how many will not see themselves in this role (Aasbo et al., 2016, Hughes et al., 2013, Knowles et al., 2016). The focus is on the primary relationship in which the caring situation is set rather than who is carer and cared for.  This approach attempts to provide consistency for all involved and there is support in a person centred holistic way. This was an area which was poorly covered in the literature despite the workforce development resource specifically available for this (NHE Education for Scotland, 2013). Only one study recognised staff training importance in its role in supporting carers and this was Australia (Bronson and Toye, 2015).

The context in which the term carer has developed can't be ignored as the politicisation which is now associated with it does have implications.  Carers UK and the National Carers Organisations have fought a hard campaign to establish rights for carers and the word entitlement is frequently accompanied by the term   (Carers UK, 2016b, National Carers Organisations 2015)..   When considering the arguments put forward by Molyneaux (2011) of how it has turned what they describe as a normal human experience into a socio-political construct linked to accessing support, their assertion that it will impact on use of services is a valid one.  If people don't see themselves as carers they are not going to access carer support services. The irony is this is well documented by Carers UK the main driver of this (Carers UK, 2016a)

This does have direct implications when considering the above point with the aims of the Carers (Scotland) Act.  The original intent of the Act is to support those who wish to care and that they can do so in good health with a life alongside caring.  Yet the hospital duty could be considered to shoehorn relatives and friends into a caring role.  Several studies found staff assumptions on provision of support were acted on with varying levels of confirmation with relatives of their agreement (Hughes et al., 2013, Knowles et al., 2016, Laing and

Sprung, 2013, O'Connor, 2007, Seddon and Robinson, 2015).  Camden et al., (2011) went so far as to exclude spousal carers from their study looking at who become carers on the assumption that it is unusual for a spouse not to be the primary carer.

There is certainly more evidence in the literature which is of a negative nature on the use of the term carer than it being an enabler as contended by the campaigning arm of carer support Carers UK.

## 6.3 Relationships and recognition of role

The case relating to definition of carer has been considered in 6.2 but is intertwined with this section.  Links to personal identity and maintaining normality are well argued by a number of authors, particularly as they consider this from the perspective of both parties in recognition of the caring role (Aasbo et al., 2016, Hughes et al., 2013, Knowles et al., 2016, Milligan and Morbey, 2016, Molyneaux et al., 2011, O'Connor, 2007, Popejoy, 2011).

Aasbo et al. (2016) "biographical we", the efforts to maintain routine and continuity in the relationship, accurately describes what was found with many of the participants in this study. For some the adaptations reported in order to maintain some link with the previous life prior to the hospital admission were substantial.  One participant reported concerns adaptations made to the house to try avoid requiring formal services were likely to be insufficient.  Another described living part time near his father and part time with his partner in order to preserve both previous existences.  It should be noted both of these participants acknowledged they were carers when asked but initially described themselves in the primary relationship.

The notion of liminality as described by Gibbons et al., (2014) was exhibited by a number of participants in this study.  The idea there is a rite of passage which requires to be transcended was very evident with one participant in particular.  At the beginning of the interview the role ambiguity associated with this

concept, was expressed when it transpired roles had been reversed. Prior to his hospitalisation her husband had cared for her. They were now faced with the reality where despite her own substantial health problems, she would require to assume the caring role. This was recognised by the participant but there was also a lot of concern and stress as to what this would mean for them as a couple. How this was playing out on the ward was a difficult relationship with staff, including trust issues. The participant did not even recognise the interactions she was having with staff.

### 6.3.1 Duty and responsibility

The notion of duty and responsibility were raised within this study. For one participant it appeared to be associated with guilt. They were at great pains to let the researcher know the support they were providing was not a duty but they were doing what the patient had done for them when they were ill.

Various degrees of duty and responsibility and how this is exhibited is described elsewhere in the literature. Al-Janabi et al., (2008) acknowledged how language is interpreted has a role to play in this relationship dynamic. While Alanabi et al. express duty from a positive perspective of fulfilment, while Knowles et al., (2016) associates this with role responsibilities which once changed often lead to assumption of the caring role.

### 6.4 Strain and resilience

The dominance in the research to consider the role of carer from a burden perspective is overwhelming. While there is a vast body of evidence to support the negative impacts that caring can have on an individual's health and wellbeing it could be contended that if you look only in one direction you will only get one answer. There is almost a self-fulfilling prophecy attached to becoming a carer that asserts you will become burdened, an association often found in reports from Carers UK (Carers UK, 2016a, Carers UK, 2016b). It is somewhat troublesome when papers published associate reasons for why family members

become carers with development of abusive behaviour towards the cared for (Camden et al., 2011).

This study did find evidence of both strain and resilience expressed by a small number of participants.    However, the content of conversations as recalled by participants did not evidence any exploring by staff on these components.  There requires to be a triangulated approach involving patient staff and relatives to fully explore this aspect.

Even most of the tools designed for staff to identify potential support needs are deficit and burden based (Al-Janabi et al., 2008, Robinson, 1983). This is a particular concern within the acute hospital setting as it is likely there will require to be some form of tool to assist staff in identifying, involving and supporting those relatives and friends supporting patients.

## 6.4 Acute hospital setting and staff role

There are a number of concerns highlighted in (Seddon and Robinson, 2015) study which have particular importance for meeting the requirements of the Carers (Scotland) Act within the acute hospital setting.  Their findings may be from a social care perspective but the factors identified are also prevalent within the hospital setting.  Some of these same issues have been found in this study. Each point from Seddon and Robinson's findings will be considered alongside the findings from this study and other literature.

### 6.4.1 Practitioner ambivalence, process and time

Seddon and Robinson (2015) assert practitioner ambivalence to engage with carers is fuelled by lack of time, uncertainty over process and confusion of who they are assessing, the carer or cared for. It is also complicated further by carers inability to ascertain why assessments includes them.

Only time was identified as a factor for participants in this study.   However there are several factors associated with Seddon and Robinson (2015) finding which

are of particular relevance to the acute hospital setting. The impact of practitioner ambivalence has already been covered in 6.1.1.

A strong argument linking all three factors to a reduction in quality of nursing care is presented by Bail and Grealish in the construct of the quality indicator "failure to maintain" (Bail and Grealish, 2016). As time constraints force staff to prioritise care delivery. They found communication was omitted in up to 80% of cases when nurses made judgements on time versus effort and value with psychosocial issues often given the lowest priority. With a number of participants describing how busy the clinical area was and this had impacted on how often they had been able to have conversations with staff, this could have implications for being able to achieve the level of communication envisaged for meeting the requirements of the Carers (Scotland) Act.

There are some findings in this study which are poorly covered within the literature.
Much has been written looking at language and the use of the term carer as described in 6.2 However what this study has identified is a gap on how best the caring situation is explored in the acute environment if the requirements of the Carers (Scotland) Act are to be attained. This could be an important area for future research.

**Study strengths and limitations**
This is a small scale qualitative study which adds to the body of evidence relating informal carers. It appears to be the first study in Scotland to consider the context of communication in an acute hospital setting from a broad perspective of exploring the caring situation.

The majority of studies to date in the acute setting has been narrowly focused on condition specific factors and burden based. This study adds to the understanding of what values relatives / friends give to the conversations with

staff as well as the deficits in relation to the expectations of the Carers (Scotland) Act.

A detailed insight has been obtained into the lived experience of participants' views and meanings given to their interactions with staff.

Recall bias is a risk

While numbers are small and therefore are not generalizable, the findings have provided very good insight into the role of effective communication in order for the caring situation to be discussed.  This is within settings where there is already an expectation of this level of engagement.  What this has highlighted is the need for a system wide approach if the requirements of the Act are to be met.

## 7. CONCLUSIONS AND RECOMMENDATIONS

The term carer is a label which is not widely accepted by those who meet the definition immediately creating an inequality in access to services to support them.  Even for those who do accept the label, there is a reluctance to engage with services.   The complexities around the non-engagement with support may have some commonalities with usual barriers to linking with services but on the whole this remains unclear.  Support for carers appears a maze that both carers and services find difficult to fathom from an acute hospital setting.  There is a need to consider a complex systems model of evidence for this topic to help identify how interventions are contributing to systems and improving favourable outcomes (Rutter et al., 2017).

The political nature of this subject means there will require more open debate within society.   Today's social structures and non-nuclear families are very different to when current systems were established.    For the acute hospital environment, there requires to be a normalising of the topic being discussed with clarity on who can be called on to support.

The focus of conversations in acute hospital environment is rooted in the immediate timeframe for most. There remains an emphasis on the biomedical components by relatives, patients and staff.  Psychosocial issues which have a major impact on a person's ability to self-manage their health and wellbeing such as support form unpaid carers, continues to be an afterthought.

### Recommendations

This study was limited to those providing a support role.  In order to fully explore if the current process within NHSGGC meets the aims of the hospital duty of the Carers (Scotland) Act a further piece of work should focus on triangulation to include all groups involved in the decision making for discharge.

Workforce development requires staff to have a better understanding of the complexities for patients and their relatives / friends to recognise support

requirements of all involved. This should be supported by systems and processes including documentation which improve the clarity around the support arrangements for patients.

The specific needs of carers in the acute environment is not fully known. With shortening length of stay, there requires to be recognition that the acute environment is just one opportunity for healthcare staff to explore the topic with patients and their unpaid care support. Further exploration of how information is shared across sectors and between agencies both statutory and voluntary requires to include carers alongside those currently being explored for child protection.

**8. LESSONS LEARNED**

Reflexivity is a now a well-developed tool which I have come to value through the course of this project.

I chose this topic to gain a better understanding of what needed to be done to improve the journey for those supporting carers.  This process has demonstrated to me that even though there is a legislative intent, there also requires a culture shift which may not be in step with meeting that intent.

**REFERENCES**

Aasbo, G., Solbraekke, K. N., Kristvik, E. & Werner, A. 2016. Between disruption and continuity: challenges in maintaining the "biographical we' when caring for a partner with a severe, chronic illness. *Sociology of Health & Illness,* 38**,** 782-796.

Agard, A. S. & Maindal, H. T. 2009. Interacting with relatives in intensive care unit. Nurses' perceptions of a challenging task. *Nurs Crit Care,* 14**,** 264-72.

Al-Janabi, H., Coast, J. & Flynn, T. N. 2008. What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up. *Social Science Medicine,* 67**,** 111-21.

Anke, A., Manskow, U. S., Friborg, O., Roe, C. & Arntzen, C. 2016. The family experiences of in-hospital care questionnaire in severe traumatic brain injury (FECQ-TBI): a validation study. *Bmc Health Services Research,* 16.

Arksey, H., Glendinning, C. 2006. Choice in the context of informal care-giving. *Health & Social Care in the Community,* 15**,** 165-175.

Bail, K. & Grealish, L. 2016. 'Failure to Maintain': A theoretical proposition for a new quality indicator of nurse care rationing for complex older people in hospital. *International Journal of Nursing Studies,* 63**,** 146-161.

Baker, S. E. & Edwards, R. 2012. How many qualitative interviews is enough. National Centre for Research Methods Review Paper.

Bélanger, L., Bourbonnais, A., Bernier, R. & Benoit, M. 2016. Communication between nurses and family caregivers of hospitalised older persons: a literature review. *Journal of Clinical Nursing,* 26**,** 609-619.

Bloomer, M., Digby, R., Tan, H., Crawford, K. & Williams, A. 2014. The experience of family carers of people with dementia who are hospitalised. *Dementia*.

Boltz, M., Chippendale, T., Resnick, B. & Galvin, J. E. 2015. Anxiety in Family Caregivers of Hospitalized Persons With Dementia Contributing Factors and Responses. *Alzheimer Disease & Associated Disorders,* 29**,** 236-241.

Bowling, A. 2014. *Research Methods in Health: investigating health and health services,* Maidenhead, Open University Press.

Bronson, M. & Toye, C. 2015. Providing information for family carers of hospital patients experiencing dementia. *Dementia (London),* 14**,** 267-72.

Buckner, L., Yeandle, S. 2015. Valuing Carers 2015 - the rising value of carers' support

Carers UK. London: Carers UK.

Camden, A., Livingston, G. & Cooper, C. 2011. Reasons why family members become carers and the outcome for the person with dementia: results from the CARD study. *International Psychogeriatrics,* 23**,** 1442-1450.

Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J. & Murray, S. A. 2014. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Family Practice,* 15**,** 48.

Carers (Scotland) Act 2016. Edinburgh:TSO.  Retrieved from: http://www.legislation.gov.uk/asp/2016/9/contents/enacted.

Carers UK, 2016b. State of Caring 2016.

Carers UK. 2015a. The Health and Wellbeing of Unpaid Carers.

Carers UK. 2016a. Missing out: the identification challenge. Carers UK

CASP. 2017. CASP Tools & Checklists [Online].  Available: http://www.casp-uk.net/casp-tools-checklists.

Chapman, A. L., Hadfield, M. & Chapman, C. J. 2015. Qualitative research in healthcare: an introduction to grounded theory using thematic analysis. *The Journal of the Royal College of Physicians Edinburgh,* 45**,** 201-5.

Charmaz, K. 2014. *Constructing Grounded Theory,* London, SAGE Publications Ltd.

Colorafi, K. J. & Evans, B. 2016. Qualitative Descriptive Methods in Health Science Research. *HERD: Health Environments Research & Design Journal,* 9**,** 16-25.

Creswell, J. W. 2013. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches.,* London, Sage Publications.

Davidson, J. E., Jones, C. & Bienvenu, O. J. 2012. Family response to critical illness: Postintensive care syndrome-family. *Critical Care Medicine,* 40**,** 618-624.

Davies, M. & Hughes, N. 2014. *Doing a Successful Research Project: using qualitative or quantitative methods.,* Basingstoke, Palgrave Macmillan.

Finlay, L. 2002. "Outing" the Researcher: The Provenance, Process, and Practice of Reflexivity. *Qualitative Health Research,* 12**,** 531-545.

General Medical Council. 2013. *Good medical practice (2013),* London, General Medical Council.

Gibbons, S. W., Ross, A. & Bevans, M. 2014. Liminality as a conceptual frame for understanding the family caregiving rite of passage: an integrative review. *Res Nurs Health,* 37**,** 423-36.

Green, J. & Thorogood, N. 2014. *Qualitative Methods for Health Research* London, Sage Publications Ltd.

Griffiths, J., Hatch, R. A., Bishop, J., Morgan, K., Jenkinson, C., Cuthbertson, B. H. & Brett, S. J. 2013. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. *Critical Care,* 17.

Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin, L. 2016. Registered Nurses' Perceptions about the Situation of Family Caregivers to Patients with Heart Failure - A Focus Group Interview Study. *Plos One,* 11.

Haines, K. J., Denehy, L., Skinner, E. H., Warrillow, S. M., & Berney, S. 2015. Psychosocial Outcomes in Informal Caregivers of the Critically Ill: A Systematic Review*.[Review]. *Critical Care Medicine,* 43**,** 1112-1120.

Henriksson, A. & Arestedt, K. 2013. Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine,* 27**,** 639-646.

Hughes, N., Locock, L. & Ziebland, S. 2013. Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis☆. *Social Science & Medicine,* 96**,** 78-85.

Jurgens, F. J., Clissett, P., Gladman, J. R. F. & Harwood, R. H. 2012. Why are family carers of people with dementia dissatisfied with general hospital care? a qualitative study. *Bmc Geriatrics,* 12.

Khabarov, D., Dimitropoulos, G. & Mcgillicuddy, P. 2015. Qualitative Study: Exploring the Experiences of Family Caregivers within an Inpatient Neurology and Neurosurgery Hospital Setting. *Health & Social Work,* 40**,** 290-7.

Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N. & Sanders, C. 2016. Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community.*

Laing, M. & Sprung, S. 2013. Literature Review: Working with Health Care Professionals to Increase Care Awareness, Identification and Referral. Available: http://www.qni.org.uk/supporting_carers/carers_project_resources.

Mcpeake, J., Devine, H., Mactavish, P., Fleming, L., Crawford, R., Struthers, R., Kinsella, J., Daniel, M., Shaw, M. & Quasim, T. 2016. Caregiver strain following critical care discharge: An exploratory evaluation - Journal of Critical Care. *Journal of Critical Care,* 35**,** 180-184.

Milligan, C. & Morbey, H. 2016. Care, coping and identity: Older men's experiences of spousal care-giving. *Journal of Aging Studies,* 38**,** 105-114.

Molyneaux, V., Butchard, S., Simpson, J. & Murray, C. 2011. Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. Ageing & Society, 31, 422-437.

Morrow, E. M. & Nicholson, C. 2016. Carer engagement in the hospital care of older people: an integrative literature review. *International Journal of Older People Nursing,* 11**,** 298-314.

National Carers Organisations. 2015. Draft National Eligibility Framework for Carers - Carers UK. Carers Scotland.

National Records For Scotland. 2011. Scotland's Census 2011.

Newell, R. 2011. *Research for Evidence-Based Practice in Healthcare,* Chichester, Wiley.

NHS Education for Scotland. 2013. Equal Partners in Care (EPiC): Core principles for working with carers and young carers. Edinburgh: NHS Education for Scotland.

NHS Greater Glasgow and Clyde. 2016. Working in Partnership With Carers: Acute Division Carers Information Strategy Update. Glasgow: NHS Greater Glasgow and Clyde.

Nursing and Midwifery Council. 2015. *The Code: professional standards of practice and behaviour for nurses and midwives.,* London, NMC.

O'Connor, D. L. 2007. Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies,* 21**,** 165-174.

Perry, L. & Middleton, S. 2011. An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia. *Disability and Rehabilitation,* 33**,** 1890-1900.

Plank, A., Mazzoni, V. & Cavada, L. 2012. Becoming a caregiver: new family carers' experience during the transition from hospital to home. *J Clin Nurs,* 21**,** 2072-82.

Pope, C. & Mays, N. 2006. *Qualitative Research in Health Care, 3rd Edition,* London, BMJ Book Blackwell Publishing Ltd.

Popejoy, L. L. 2011. Complexity of Family Caregiving and Discharge Planning. *Journal of Family Nursing,* 17**,** 61-81.

Robinson, B. C. & Posthospital Supports Study, H. S. R., Division of Family and Community Medicine, University of California. San Francisco1487 Fourth Avenue, San Francisco, Ca 94143. 1983. Validation of a Caregiver Strain Index. *Journal of Gerontology,* 38**,** 344-348.

Rutter, H., Savona, N., Glonti, K., Bibby, J., Cummins, S., Finegood, D. T., Greaves, F., Harper, L., Hawe, P., Moore, L., Petticrew, M., Rehfuess, E., Shiell, A., Thomas, J. & White, M. 2017. The need for a complex systems model of evidence for public health. *The Lancet*.

Scottish Executive Health Department, 2006. Research Governance Framework for Health and Community Care. 2nd Edition ed.

Scottish Government. 2010. Caring Together: The Carers Strategy for Scotland 2010 - 2015. Edinburgh: Scottish Government.

Scottish Government. 2013. Route Map to the 2020 Vision for Health and Social Care. Edimbugh: Scottish Government.

Scottish Government. 2015. Scotland's Carers. Edinburgh: Scottish Government.

Scottish Government. 2017. Health and Care Experience Survey 2015/16. Edinburgh: Scottish Government.

Scottish Health Council. 2014. Teach-back. Scottish Health Council.

Scottish Parliment. 2015. Stage 1 Report on the Carers (Scotland) Bill. The Scottish Parliament.

Seddon, D. & Robinson, C. 2015. Carer assessment: continuing tensions and dilemmas for social care practice. *Health & Social Care in the Community,* 23**,** 14-22.

Silverman, D. 2013. *Doing Qualitative Research A Practical Handbook Fourth Edition,* London, SAGE Publications Ltd.

Stirling, C., Lloyd, B., Scott, J., Abbey, J., Croft, T. & Robinson, A. 2012. A qualitative study of professional and client perspectives on information flows and decision aid use. *BMC Medical Informatics and Decision Making,* 12**,** 26.

Taylor, B. & Francis, K. 2013. *Qualitative Research in the Health Sciences: Methodologies, Methods and Processes,* London, Routledge.

Tod, M. A., Kennedy, F., Stocks, A.-J., Mcdonnell, A., Ramaswamy, B., Wood, B. & Whitfield, M. 2016. Good-quality social care for people with Parkinson's disease: a qualitative study. *BMJ Open,* 16.

University of Glasgow,  2014. Code of Good Practice in Research. Version 2.1 ed.

Walker, E. & Dewar, B. J. 2001. How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing,* 34**,** 329-337.

Whittamore, K. H., Goldberg, S. E., Bradshaw, L. E. & Harwood, R. H. 2014. Factors associated with family caregiver dissatisfaction with acute hospital care of older cognitively impaired relatives. *Journal of American Geriatriatric Society,* 62**,** 2252-60.

Williams, A. P., Peckham, A., Kuluski, K., Lum, J., Warrick, N., Spalding, K., Tam, T., Bruce-Barrett, C., Grasic, M. & Im, J. 2015. Caring for Caregivers: Challenging the Assumptions. *Healthcare Papers,* 15**,** 8-21.

Yedidia, M. J. P. & Tiedemann, A. P. 2008. How Do Family Caregivers Describe Their Needs for Professional Help? *American Journal of Nursing,* Volume 108**,** 35 - 37.

# INVITATION LETTER
## Conversation on Caring Situation Study

We would like to invite you to take part in a research study.

**If you do not wish to participate please feel free to ignore this letter.**

Researchers at the University of Glasgow are seeking people to participate in interviews. The study aims to build a better understanding of the conversations taking place in hospitals around the support provided by family and friends in relation to care needs of the patient. Participation involves taking part in a face to face or telephone interview lasting no more than one hour at a time convenient to you.

The attached Participant Information Sheet provides full details of the study and what involved.

Should you wish to discuss the research further, receive an electronic version of the study materials or take part in the study please contact the main researcher Elaina Smith.  Contact details below:

- Email:  elaina.smith@ggc.scot.nhs.uk
- Address:
  Acute Health Improvement Team,
  1$^{st}$ Floor West House,
  Gartnavel Royal Hospital,
  1055 Great Western Road,
  Glasgow G12 0XH
- Telephone:
  - Mobile:  07896 937717
  - Team Secretary:  0141 201 4876

**Thanks you for taking the time to read this letter**.

Best wishes

Elaina Smith
Health Improvement Senior Acute Carers Information

# PARTICIPANT INFORMATION SHEET
## Conversation on the Caring Situation Study

**Invitation to take part in a research study**

You are being invited to take part in a research study. The study is being carried out by Elaina Smith (Health Improvement Senior NHS Greater Glasgow and Clyde) as part of Master of Public Health degree at the University of Glasgow.

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If anything is unclear or you would like more information then please ask.

**What is the purpose of the study?**

The purpose of this study is to build a better understanding of conversations taking place in hospitals around the support provided by family and friends in relation to care needs of the patient.

**Why have I been chosen?**

We are asking you to participate in this study because you have a relative/friend who is currently in hospital.  Around 20 people will be taking part in this study.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be provided with a copy of this information sheet to keep. We will also ask you to sign a consent form and provide you with a copy for your records.  If you decide to take part, you are still free to withdraw at any time and without giving a reason.

**What will happen to me if I take part?**

This study involves a single face to face interview lasting no more than one hour.  You will be asked a number of questions on your experience of conversations relating to caring taking place in the hospital setting.  With your consent, the interview will be recorded via digital voice recorder.  If you do not consent to recording then notes will be taken during the interview.  The  interview will  be arranged at a time convenient to you. It will take place in a private room either within the ward or another convenient NHS premises.

**What do I have to do?**

If you are interested in taking part in this study, contact the researcher direct by the methods detailed below.

**What are the possible disadvantages and risks of taking part?**

There is a small possibility that some questions may lead you to think of certain experiences in your life that you find upsetting. You are free to stop the interview at any point. If you would like more information or to talk to someone you will be provided with a list of contacts.

**What are the possible benefits of taking part?**
While participating in this study is unlikely to benefit you directly, the information collected will give us a better understanding of conversations taking place in hospital settings around care needs. This could benefit some patients/relatives/friends in the future.

**Will my taking part in this study be kept confidential?**
Your participation and all information you provide in the study is strictly confidential. You will be identified by an ID number and personal information (including your name and contact details) will be held separately to your answers and never linked to what you tell us in the study. All records will be stored securely in NHS Greater Glasgow and Clyde and destroyed after 1 year. Please note that assurances on confidentiality will be strictly adhered to unless evidence of serious harm, or risk of serious harm, is uncovered. In such cases the NHS Greater Glasgow and Clyde may be obliged to contact relevant statutory bodies/agencies.

**What will happen to the results of the research study?**
The results will form the basis of the researcher's Masters Project. A summary of the results will be available at the end of the study. This will be shared as part of NHS Greater Glasgow and Clyde Patient Carers Experience process. It may also inform any additional research to be commissioned on the topic by NHS Greater Glasgow and Clyde. The results may also be published in an academic journal but will not mention you.

If you would like to receive a copy of the results summary, please get in touch using the contact details at the end of this sheet.

**Who is organising and funding the research?**
This research is part of ongoing evaluation undertaken in NHS Greater Glasgow and Clyde Acute Division.

**Who has reviewed the study?**
The project has been reviewed by the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee.

**Contact for Further Information**
If you have any questions or require further information please contact Elaina Smith
- Email:  elaina.smith@ggc.scot.nhs.uk
- Telephone:
    - Mobile:  07896 937717
    - Team Secretary:  0141 201 4786
- Address: Acute Health Improvement Team, 1st Floor West House, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH

# Thank you for taking time to read this information sheet.

**University of Glasgow | College of Medical, Veterinary & Life Sciences**

APPENDI

**NHS Greater Glasgow and Clyde**

**X 3 – Consent Form**
Centre Number:
Project Number:
Subject Identification Number:

## CONSENT FORM

**Title of Project:**          **Conversations on Caring Situation Study**

**Name of Researcher(s):**     **Elaina Smith**

I confirm that I have read and understand the information sheet dated 20th Oct 2015 (version1.2 ) for the above study and have had the opportunity to ask questions ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

I agree to take part in the above study. ☐

I agree to the interview being digitally audio recorded. ☐

OR

 I agree to notes being taken ☐

I agree that anonymised quotations can be used in relevant reports or publications that may come out of this research ☐

---

| | | |
|---|---|---|
| Name of subject | Date | Signature |

| | | |
|---|---|---|
| Name of Person taking consent (if different from researcher) | Date | Signature |

| | | |
|---|---|---|
| Researcher | Date | Signature |

(1 copy for subject; 1 copy for researcher)

**APPENDIX 4 – Interview Schedule**

**NHS Greater Glasgow and Clyde**

# INTERVIEW SCHEDULE
## Conversation on Caring Situation Study

As a means of gaining greater insight into the on-going evaluation of current process for identifying carers within NHS Greater Glasgow and Clyde Acute Division, the following lines of enquiry will be followed during a face to face interview with relatives/friends self-selected to participate.

- Have you been engaged in conversations with staff about the caring situation at home while Patient X has been in hospital? Including:
    - Current situation at home
    - Have you been referred to as a "carer"? By who? In what context? When (from beginning or later in the situation?
    - Do you see yourself as a "carer"? If yes why/If no, why?
- Which staff have discussed this? Including:
    - How introduced
    - When introduced
    - Who initiated
- What was the outcome of the conversation? Including:
    - Was an action plan identified?
    - Was this negotiated?
    - How satisfaction with the process were you?

Interviews will take place at a mutually convenient time on NHS premises.

Interviews will be recorded via digital voice recorder and last no longer than one hour.

**APPENDIX 5 – Ethics Approval**

![University of Glasgow | College of Medical, Veterinary & Life Sciences]

Dr Dorothy McKeegan
College Ethics Officer

Senior Lecturer
R303 Level 3
Institute of Biodiversity Animal Health and
Comparative Medicine
Jarrett Building
Glasgow G61 1QH Tel: 0141 330 5712
E-mail: Dorothy.McKeegan@glasgow.ac.uk

30th October 2015

Dear Ms Reilly

**MVLS College Ethics Committee**

**Project Title:** Exploring the outcome of conversations on the caring situation within the acute hospital setting

**Project No:** 200150018

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 31st August 2016
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

*Dorothy McKeegan*