

'CARE FOR ME AT HOME'

A Qualitative Exploration of Experiences of People receiving Domiciliary (Home) Care in the London Borough of Bexley

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“Well I know perfectly well that I couldn’t do without the help, I do need the help. Having the help obviously does improve the quality of my life that’s left”

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Authors' contributions

DP wrote the report. LW was a reviewer and author of the literature review. EH reviewed drafts of the report and assisted with the data analysis as did RH. CB assisted with drafting findings. Interviews were undertaken by NR, LH and AHM and transcribed in full by NR. All authors read and approved the final manuscript. The Bexley Healthwatch Board approved the report in January 2016.

CONTENTS

Authors' contributions	1
INTRODUCTION	4
A REVIEW OF THE LITERATURE.....	7
The context of domiciliary care services	7
Defining domiciliary care.....	7
Defining 'good' care.....	8
Challenges facing the sector	9
The social market in care and the 'choice' agenda.....	11
Funding and evaluating domiciliary care.....	14
Care relationships.....	14
Measuring quality of care.....	16
Raising the standards of service provision	17
Evaluating domiciliary care.....	22
Conclusions and recommendations from the literature reviewed	23
HOME CARE IN ENGLAND – THE LOCAL VERSUS THE NATIONAL CONTEXT	28
METHODOLOGY	30
Demographic data.....	31
Recruitment	34
Data Analysis	34
FINDINGS.....	36
Summary.....	36
Overall quality of Home Care	36
Qualitative findings.....	37
Summary	37
Analysis of Themes from Interviews.....	41
<i>The role of Home Care – summary of care received and potential difficulties.....</i>	<i>41</i>
<i>Home care: why it is needed – changing realities.....</i>	<i>46</i>
<i>Transitions: 'home' as a changing space – adaptations, the first step.....</i>	<i>48</i>
<i>Adapting to survive.....</i>	<i>51</i>
<i>'Home': no longer a private space – conflicting feelings</i>	<i>53</i>
<i>The Organisation of home care choice: the next step – influence on type and level of care</i>	<i>55</i>

<i>Logistical implications - timings and lateness</i>	63
Tolerance and empathy for workers and providers:	70
<i>Lack of consistency - carer regularity</i>	72
<i>The caring relationship - Positive carer interactions</i>	78
<i>Professional distance - in the absence of close carer relationships</i>	83
<i>Cultural expectations: communicating need</i>	84
<i>Lack of training, stress and pressure - barriers to good care</i>	87
<i>Unmet needs – Loneliness and isolation, facilitating community involvement and independence</i>	90
<i>Transport issues – feeling trapped or isolated</i>	94
<i>Home care as respite for family carers</i>	96
<i>Feedback and complaints</i>	100
<i>Care recipient recommendations</i>	103
1. Time-keeping	103
2. Quality and scope of care	103
3. Nothing to improve	105
4. Ambiguous/ neutral responses.....	105
 RECOMMENDATIONS	107
 1. Facilitating access to community networks: reducing isolation	107
2. Maintain high monitoring standards	108
3. Improve choice of type and level of care	109
4. Improve information on other services	109
5. Smooth transition from hospital to home care	110
6. Effective Communication and continuity of care	110
7. Further research and development	111
 REFERENCES	112
 APPENDICES	123
<i>Appendix 1 - Abbreviations</i>	123
<i>Appendix 2 - Web-based resources</i>	123
<i>Appendix 3 - Domains of outcomes: Malley and Netten 2008</i>	123
<i>Appendix 4 TOPIC GUIDE</i>	124

INTRODUCTION

The terms 'Domiciliary Care' or 'Home Care' encompass a variety of services that are set in the private homes of people who need support with personal needs ranging from complex medical interventions to day-to-day household activities. Home care is critical in supporting other NHS and statutory services as it keeps people out of expensive and inappropriate acute services and allows people to return home where they, generally, feel more comfortable, safer and where they can regain some independence. Regaining independence and self-determination are core goals of social care services and supporting people to stay in their own homes, close to their friends, families and social support is at the heart of domiciliary care. The workforce is generally poorly paid and under-skilled considering the range of competences expected of it – from domestic cleaning and shopping to intimate services and complex medical interventions (Bolton and Wibberley, 2013). The workforce has to not only to provide personal *care* but also to demonstrate technical skill in challenging workplaces with vulnerable people.

Government policy on domiciliary care, broadly defined, focuses on promoting user 'choice' in services and, through direct payments, aims to empower the users of services to define the type of care they receive. At the same time the criteria for publicly funded care has become very strict so that only the most in need are eligible. Political ideologies in the face of increasing demand for services in straitened economic times have favoured private over public services and have led to the development of the 'social market of care' and the privatisation of services. This means that local authorities act as commissioners of services more often than as providers.

'Choice' is inherently subjective and for service users to enjoy real choice their views have to be paramount and their decisions on prioritising spending respected. Users represent all demographic categories and have many different levels of capability and capacity. Some service users are socially able and are well supported by their social networks; they may be well able to express their requirements of services. Others, however, will be more dependent on service providers to design their care packages (for example people with cognitive impairments) and may be unable or unwilling to

challenge or question the services they receive. Ensuring this group is able to have their subjective health needs met and their choices respected requires special attention. The safeguarding of both service users and carers is another area of crucial importance to this sector. The workplace, in private homes, is potentially unsafe for both carers working alone and the vulnerable people they look after. Carers have to be trusted by the people they care for but at the same time service users may not have easy and effective forms of redress if they are unhappy about the care they receive. Monitoring and evaluating services is a key way to ensure quality of services but the subjective nature of care requirements means that effective service evaluation needs to proactively involve users in evaluating not just the caring activities and tasks performed in the home but also the clients perception of care relationships and satisfaction with the care package as a whole.

The quality of life for those who receive domiciliary care is an under researched area. More attention has been focussed on the quality of care given to residents not least following evidence of abuse of vulnerable older people in care homes. While good quality care can enhance the quality of life for residents it is a different concept. Commissioned by the London Borough of Bexley, this study explores the perspectives of people receiving domiciliary care in the Outer London Borough of Bexley. This research developed the work already undertaken by councillors in their Reality Testing visits by capturing the views of recipients themselves (and their families as proxies where they are unable to communicate). The aim of the study was to investigate the feelings and experiences of recipients of home care using qualitative oral history research methods. Significantly this study has important educational benefits, giving the recipients of Home Care the opportunity to speak out about their experiences, thereby generating awareness in public attitudes towards the complex issues of Home Care. Individual 'voices' narrate stories, express opinion, and so contribute to the on-going discourse within health and social care. The equitable nature of oral history, which values individual subjective knowledge, supports the incorporation of the findings into the discussion and allows them to give validity in the debate and analysis. In this report, the qualitative data provide in-depth insights into the phenomena under consideration and allow themes to emerge. These themes are analysed more extensively, related to current empirical evidence from England and UK studies and, based on this analysis, recommendations are drawn for policy and practice.

Findings from this report will be disseminated through an oral and visual exhibition which will be deposited in Bexley library, thus, continuing the Council's and Healthwatch Bexley's work to generate awareness in public attitudes towards the complex issues raised. The results of the study will be presented to the Bexley Health and Wellbeing Board in January 2016. A report will be given to the Director of Adult Social Care for London Borough of Bexley, Healthwatch Bexley, Healthwatch England and the Department of Health and articles will be submitted to peer-reviewed publications. A summary of the results will be made publicly available on the Healthwatch website, and further arrangements for the dissemination of the findings will be discussed with the London Borough of Bexley funders. It is hoped that this research will provide valuable information for commissioners and service providers in working towards improving Home Care services and standards of care.

A REVIEW OF THE LITERATURE

The literature review considers home-based services for the elderly, the disabled and anyone requiring help because of physical or mental illness and infirmity. It begins by outlining the broad context of care services, looking closely at what is meant by 'domiciliary care' and considering the range of services and settings it encompasses. It should be noted here that the regulation of care services is devolved to the different nations of the UK; this review focuses on England.

The context of domiciliary care services

Defining domiciliary care

Domiciliary care covers a broad range of activities including help to cook, clean and shop as well as personal and intimate care services such as bathing and toileting. Care may include activities inside the house such as dealing with household bills as well as help getting out of the house to attend appointments and leisure activities (Boerma et al 2011). The social element of domiciliary care allows people with chronic (or sometimes acute) care needs to enjoy fulfilling everyday lives. For some, domiciliary care needs will include medical care and this may be aimed at rehabilitation after short-term illness. For others care will be longer term, for example as part of a palliative care programme which may start as care provided for a few hours a day increasing to full-time caring. Domiciliary care services may support people with mental health problems, ensuring that they develop and enhance social and other skills to keep them well and offer practical support with a range of daily activities. Similarly, many people with learning disabilities, from mild to moderate and severe will need support on an ongoing basis. Service users needing regular support may also need occasional periods of extra and more intensive support as part of re-enablement programmes. This may be after episodes of ill health or changes in their conditions that have left them needing support to convalesce or rebuild skills and confidence.

Good domiciliary care should, first and foremost, be person-centred and respect for individual practical and emotional needs should be embedded in the job and not be seen as an add-on (Joseph Rowntree Foundation, 2011). The actual mix of practical, emotional and technical tasks performed by carers should be determined by the

services user and their representatives through the care planning process and agreeing how individual needs can be met in what are often very short interactions between carer and the person they care for will be discussed further below. It is essential that the subjective nature of wellbeing and of the assessment of care should be kept in mind and it is important to recognise that 'good care' will differ from person to person.

Defining 'good' care

Domiciliary care is most often provided informally, by friends and family, some who are eligible for payment under direct payment schemes but most care work remains unpaid. Professional care services, are provided by profit-making companies or the voluntary sector and may be contracted or recommended by social service departments. The domiciliary care sector has developed over the past 20 years from being largely 'home-help' type services providing day-to-day tasks such as shopping, cooking, laundry and cleaning for the elderly and infirm to include a broad range of skilled and unskilled caring duties. In addition to this broadening of tasks and skills, the service has become increasingly marketised. Services are generally provided by agencies commissioned by local authorities or privately engaged to provide support on an hourly, or even part of an hour, basis in private homes.

Domiciliary care operates at a personal and at an institutional level. This is clear in a report written by the Commission for Social Care Inspection (CSCI, 2006), which stated that "Excellent outcomes are being achieved, ranging (at individual level) from an increase in people's health, confidence and quality of life to (at strategic level) thousands of people being helped to live quite independently without recourse to more expensive interventions." (CSCI, 2006). This two-fold remit, at individual and strategic levels, demonstrates both the challenges and the opportunities of this type of service. The place of domiciliary care in the social market of care has led to increasingly 'commoditised' care services with a tendency to break caring tasks into measurable tasks and activities. The profit motive brings with it a potential conflict of interest as the service user's dependence can be to the service provider's advantage. This conflict may be especially in evidence when services are intended to re-able their clients and promote their independence.

The personalisation agenda has been a central element in government policy since the 'Putting People First' concordat of the Department of Health (2007) and home care providers are expected to provide services which are flexible and which match the individual and changing needs of service users. Service users, however, require holistic care which reflects their personal preferences and which may challenge the assumptions built in to the services set up for them. The Coalition Government endorsed the personalisation agenda in 2010 and the direct payment system of personal budgets remains government policy.

Challenges facing the sector

In 2006, the CSCI identified the following challenges in providing home services to older people and eight years on the same issues are still relevant:

- 'Fragility' of the sector with increasing demands being placed on it.
- Have to be increasingly disabled to get state funded support – must be 'substantial' or 'critical'
- An undeveloped market and under trained staff
- Care managed through individual care plans based on prescribed activities – inflexible and rushed – counter-productive as undermines sense of being cared for (CSCI, 2006:7).

There are many safeguarding challenges inherent in providing services to a disparate group of vulnerable and potentially needy people. The most obvious challenge relates to the isolated working conditions inherent in domiciliary care. Working in people's homes, often with just the carer and the person being supported present has obvious risks for both the carer and the person cared for. Service providers may feel vulnerable to the potentially abusive behaviour of those they care for and the risks to their often frail, ill and probably socially excluded clients are self-evident. Examples of adult abuse in residential care-settings, where many people work together, are well documented and long-standing and it is fair to assume that there must be many more cases of adult abuse in private homes. Many people who need professional home care services do so because they cannot, or prefer not to, draw on personal resources such as friends or family. They may be unable or for many reasons unwilling to complain

about the services they receive. Services, therefore, need to be structured to ensure that both carers and their clients are actively supported in expressing their concerns about the care they receive and provide. In the UK, only Scotland has legislation specifically protecting adults (the Adult Support and Protection (Scotland) Act, ASPA) which was passed by the Scottish Parliament in 2007. In England, concerns about the balance between someone's right to choose and the duty to protect relies chiefly on European human rights legislation. The Department of Health (DH) and the Home Office published guidance on challenging and recognising adult abuse in 2000 (The 'No Secrets' report) which identified types of abuse as: physical, sexual, psychological, financial or material, neglect and acts of omission, discriminatory or institutional. Some forms of abuse are criminal offences, for example, physical assault, sexual assault, rape and fraud, as are forms of discrimination, such as on racial and gender grounds (DH and Home Office, 2000:9). The report provides guidance and is not binding by law but it encourages the setting up of local Safeguarding boards and advises on the complex area of data protection and information sharing.

A further major challenge to the provision of good care in the home is funding and this has become more acute in the light of wider cuts to public and welfare spending. All health and social care services are currently subject to cuts and local authorities are under great pressure to reduce their spending in this as in other areas. Glendinning argues that "Long-term care in England is widely acknowledged to be seriously under-funded, relative to levels of need. Despite sharing demographic pressures common to all European countries, there has been a continuing political failure to achieve a comprehensive, sustainable and equitable basis for funding social care in England." (2012: 293). To be eligible for support, care needs have to be assessed as increasingly severe despite broader policies that aim to keep people who living at home and out of residential care settings.

There is pressure on clients to fund, or supplement, their care from their own resources and this pressure forces clients to choose between tasks they would like to have help with in their allotted time with the carer. Funding shortages and an assumption that profit-making companies will make the best use of public funds has led to privately-provided services making local authorities more often commissioners of services than direct providers. This has implications for how services are monitored and regulated.

Since 2005 forms of personal, direct payments from local authorities have been used to pay for services and they have given many service users greater autonomy to control of their care packages and choose the services they want. An obvious problem with direct payment, however, is that some service users are unable or unwilling to take responsibility for choosing and managing their own care which, in some cases may involve becoming an employer.

The social market in care and the 'choice' agenda

In 1993 only 5 per cent of home-care services were delivered by the independent sector but by 2011 this figure had risen to 81 per cent (Lewis and West, 2014). This major change in care provision continues and is unlikely to shift back towards publicly provided care. Policy has been driven by an emphasis on 'choice' and an assumption that private companies are more likely to deliver flexible services cheaply and effectively. As Lewis and West explain "... the thinking behind social care policy for the past thirty years has been first that provider competition will drive quality, and second that empowering users as consumers in the social care marketplace will ensure they get the kind of care that they want." (2014:4) Continuing cuts to public spending has undermined this goal as there has been little investment in the social care workforce and austerity presents many barriers to choice. Older people and others requiring domiciliary care have very different needs and very different capacities and opportunities to make informed choices and get the best from care services. The assumptions behind the social market in care rely firstly, on the existence of sufficient funding for services and secondly, that service users are able and prepared to actively participate in choosing the care they want to receive. "Choice is also supposed to give service users control over their care, but in regard to home care, it is recognised that many service users still want and need help in carrying out self-assessment and in identifying the outcomes they want to achieve (Orellana, 2010). Much therefore depends on the skill levels of those carrying out assessments and negotiating budgets." (Lewis and West, 2014:9-10).

Individual Budgets (IBs), and other forms of direct payment allow users to choose their own care priorities and these payments can have an important place in promoting

choice. Stevens and colleagues evaluation (2011) of the impact of IBs, however, found that while budget holders felt more in control of their lives (especially those with learning disabilities) there were still significant problems related to power relations, equity and the constraints implied by the public nature of decision-making. IBs and other forms of direct payment were intended to give poorer people the same control over spending that wealthier, privately funded, people have and it was hoped that this would grant publicly funded recipients of care the power to dictate the care they would receive.

Clarke et al (2007, cited in Stevens et al 2011) refer to “three ‘antagonisms of choice’” which help us understand how ‘choice’ can work in public services. The first antagonism relates to choice and equity and to how the needs of different people can be balanced against each other. Stevens et al findings in this area were that the personal resources of the individuals had a marked effect on how much they could benefit from the ‘choice’ offered by direct payments. They cite a user who told them:

“I had said to [support planner] ‘Well, God, that’s not very much left to have a gardener’ and she said ‘Well that’s how it’s been worked out’. But of course then I realised and appreciated that . . . the company I’d been put into, the agency, was about the dearest there is in [council district] . . . so I thought, right, well I can do this cheaper myself so . . . I went to a smaller, cheaper and far superior agency. (Person using services)” (2011:265-267).

Clearly not every direct payment budget holder is able to take this level of responsibility for ensuring their budget is spent on the kind of care they want to receive. Stevens et al (2011) note the importance of having supportive networks to draw on when making these decisions and negotiations and Fenge (2012) argues that social workers involved in setting up these arrangements need to add financial knowledge to their repertoire of skills.

The second ‘antagonism’ relates to the public and private nature of decisions and to how care management staff may make a ‘moral’ decision about the legitimacy of individual choices. Stevens et al (2011) found evidence of staff approving some choices, such as cleaning and dressing while challenging other choices (TVs or laptops) than could be construed as luxuries and therefore not appropriate for public

funding. Normative views on choice also relates to concerns about risk and “Choice was sometimes presented by care coordinators, first line managers and other personnel with responsibility for adult protection or safeguarding as in tension with public concerns about safeguarding vulnerable adults.” (Op.cit:268).

The third antagonism relates to power and specifically to the power exerted by care coordinators and others to encourage or discourage self-determination. As well as choice being directly affected by the attitudes of care coordinators working closely with budget holders, care plans often have to signed off by more distant managers who may have different views on care and value for money. Stevens et al provide an example:

“We had such a palaver about how to word it. On the plan we put down ‘befriender’ and when we tried to get it signed off higher up, it got rejected because of that. So we all got back together and changed the word to ‘companion’. All that added an extra 4–5 days of our time. (Person using services) (2011:271).

Stevens et al (2011) work shows how, while the choice agenda works towards self-determination, the public nature of the funding constrains how money can be spent and, especially in a time of austerity, allows the moral judgements of managers and others to influence care choices. Stevens et al warn that “It is likely that those with more social capital, particularly those with active and able family carers, will be better placed to understand and manage this element, which could exacerbate inequalities.” (2011:272).

A further element of choice available to some people assessed as eligible for a care package is the choice to employ a Personal Assistant (PA) in preference to choosing an agency. A PA can give the person receiving care more control, which in turn can make care less intrusive – especially when duties involve providing intimate care (Vernon and Qureshi, 2000:264-5). A PA may be preferable for people who have a high level of dependence but who have no cognitive impairments or who are well supported by people who can help with the paperwork involved in employing a PA.

Funding and evaluating domiciliary care

Care relationships

Before domiciliary care can be improved it is necessary for thought to be given to the characteristics of 'good' care and to how it might be measured. The 'care relationship' is a key concept as it encourages a measurement of care based on interpersonal relationships rather than just activities and tasks. The subjective nature of a 'relationship' however, creates difficulties for service regulators and evaluators who find it easier to measure the 'objective' quality of services provided. Good care combines subjective and objective measures of quality and needs to be value-led, i.e. based on the best interests of the person receiving the care. It will combine softer relationship-based skills with other skills including technical competence, time keeping and value for money. Care that is perceived as being 'good' will combine objective judgements such as measurable skill in tasks and timekeeping with subjective skills such as empathy and flexibility in carrying out tasks when and how the recipient of services likes them to be done.

Focusing first on these softer, more subjective skills, a key element of any caring relationship should be the promotion of independence and autonomy. As Ware et al write:

“For care in the community to be a reality, there need to be systems in place to ensure trusted and fair services and for relationships to develop in which older people can be treated as active whole people, not simply as passive service recipients.” (2003:425-6).

Vernon and Qureshi (2000) have also argued that promoting independence, understood as autonomy and self-sufficiency, implies the ability of individuals to live the kind of life *they* want. Independence should mean that people should not have to rely on others more than is absolutely necessary within their physical and mental capacities. Vernon and Qureshi's research was based on the views of disabled and older people receiving care along with their family members and social service staff. From these interviews and focus groups a number of outcomes were identified which did, or could, enhance their lives. These are considered below.

The first requirement of good care noted by Vernon and Qureshi related to personal cleanliness and comfort. The people they talked to placed the emphasis on being 'clean' rather than being in the receipt of a bathing service. This meant that while quality standards relating to inputs specified an all over wash once a week this may not have guaranteed the required outcome from a user perspective. A similar subjective view of house cleaning was also observed with users saying that "The quality of life is knowing that the house is as (you) would like to keep it" (2000:261). The quality is in having oneself or one's house 'clean' to the subjective standard that the services user is happy with and this may not be captured in the simple measures, e.g. hours spent cleaning or baths per week, commonly used. Further outcomes identified by Vernon and Qureshi were that participants wanted to be able to move about freely at home and outside the home. Examples they give relate to how a participant's disability meant that she could not negotiate the stairs so couldn't sleep with her husband. In relation to getting outside the home, being able to get out when you wanted affected leisure activities, social contact and reduced isolation. The importance of social contact cannot be under estimated and some service users looked to their carers to provide this: "Talking for an hour to them is as important as making me bed is to me. . . . To me personally, it is more important with me not going out very much." (User quotation in Vernon and Qureshi, 2000:263).

Continuing their analysis, Vernon and Qureshi remark that service providers tend to differentiate between support they regard as a 'need' and what they consider as a 'want'. Regardless of the users' preference, personal assistance in the home tended to be prioritised by providers above getting out or participating in social activities. They quote a service user:

"There seems to be a split between needs and wants, days out are a kind of a want and you can really do without them. . . . I just feel that it's not unreasonable to have the occasional social event. . . . I don't think it's unreasonable to expect that, because it's something that non-disabled people wouldn't think unreasonable for themselves to be doing. . . ." (Vernon and Qureshi, 2000:263).

Using a Personal Assistance (PA) scheme and having one's own PA can give service users extra control and flexibility in determining the balance of caring activities and in

determining what are their own 'needs and wants'. A PA can make a big difference to a person's independence and quality of life as reported: "I've a very good social life now . . . I go for drinks, go to friends' houses, they come to me, go out to have a bite and I have a mobile phone so I can phone my PA for her to be here when I want to come back." (2003:264). In their study, Vernon and Qureshi found that, while some clients chose to be dependent, the majority wanted to contribute to their care (2003:266).

Measuring quality of care

Quantifying and measuring quality of life is complex and multi-faceted and there have been many attempts to understand the elements of care that promote this sense of subjective wellbeing. Bowling and Gabriel's research (2007) identified various themes that their respondents felt gave their lives quality. These were: social relationships; social roles and activities; leisure activities enjoyed alone; health; psychological outlook and wellbeing; home and neighbourhood; financial circumstances; and independence. These things were important for the sense of freedom they brought, for pleasure, enjoyment and satisfaction with life; mental harmony; social attachment and having access to companionship, intimacy, love, social contact and involvement, help; social roles; and feeling secure (2007:827).

Malley and Netten (2008) have itemised eight domains of outcomes that need to be considered when designing and assessing care plans for recipients of domiciliary care. These are listed in Appendix 3, and these authors have discussed ways that these domains, along with four levels of need can be used to measure the efficacy of care provision. Malley and Netten note that, wherever possible service user perspectives should be used to evaluate care and they emphasise that different outcomes will be more or less important to different individuals. They point out however, that when considering this public expenditure, the preferences of the general population also needs to be considered.

The objectives of good care should always be "...to improve the quality of life of people who use services and support and of their carers" (Netten 2011:ii) but, as we have seen, quality of life is a highly subjective thing. Aiming for a personalised service based

on co-designed care plans and outcomes has been found by Brookes et al (2013:14/18) to lead to concerns that attempting to match service user aspirations was undermining attempts to measure progress and understand outcomes. The aspirations of service users were individual and subjective and while meeting these needs is a marker of 'good care', they complicated attempts to assess outcomes, services provision and progress in service improvement.

Choice and autonomy are clearly viewed by services users and commentators alike as important markers of good quality care but Barnes et al warn that "There are practical dangers in equating well-being with autonomy, independence and choice."(2013:489). their paper argues that the elderly (and vulnerable) have to alter their expectations and normative views of wellbeing to allow for their changed and changing level of dependence. This is not to say that the elderly and others should not aspire to 'normal' fulfilling lives but that helping them to live 'well enough' should be a goal of society as a whole.

Raising the standards of service provision

The Coalition and current government are continuing with policies of personalisation and choice and the Health and Social Care Act 2012, devolving power and responsibility for wellbeing and 'wellness services' to localities. Deeming argues that "The danger of this fiercely consumerist and individualist self-directed approach to policy is the increasing fragmentation and marketisation of the social and human services" (2013:560) and connects the changes in how social care services to policies evident across welfare and social support systems. Deeming warns of the dangers of relying on consumerism and the market to regulate services that the government used to be responsible for. Despite the trend towards privatisation, the private social care market does not operate along normal business lines. Local Authorities (LAs) continue to play an important role in mediating between providers and users of services and in some ways they are themselves providers and users.

"LAs have continued to determine how much money can be spent and to set the rates paid to independent providers. Thus, while it has been increasingly expected that older people will play a key role in assessing their needs and commissioning services to meet them, regardless of whether they are in receipt

of a DP (direct payment), the social care market has remained far from being a conventional market.” Lewis and West (2014:6)

Performance measures that attempt to focus on outcomes for users are still often based on surveys rather than on inspections. The ‘time and task model’ based on identifying discreet tasks, such as shaving, washing, cleaning or preparing meals continues to be used to measure many services provided in the home and while it is useful to set out key tasks that need to be done, it can encourage a mechanistic approach to tasks that can be completed and ticked off a list. When services users are asked to comment on the care they look for, they tend to focus on relationships rather than on tasks – necessary though they are. Two reports commissioned in response to poor and undignified care in private homes and residential settings, the Pearson Report, Commission on Dignity in Care (2012) and the EHRC (2011) report *Close to Home*, both focus on care relationships but neither advocated inspection or reassessment of the structures that allowed poor care to happen.

According to Rubery et al (2013) studies of commissioning practices show that commissioning is still not addressing the effect that poor employment practices and badly managed private sector agencies have on care. They argue that commissioners are not promoting good practice among independent providers as strongly as they could and identify weaknesses in human resource policies among independent sector providers as a major barrier to long-term improvements in social care.

Service quality measurements need to be based on clear and established criteria of outcomes and processes but also need to measure how the structures underpinning the services that support disabled people to improve their own quality of life (Vernon and Qureshi, 2000:269) It has long been recognised that older and disabled people are reluctant to complain but this, along with concerns about time and capacity have been used to exclude older people and other users of domiciliary care services from being involved in arranging and evaluating care. “Too much reliance is placed on self-assessment of quality by care providers and more could be done to allow the unconstrained voices of older people to be heard by local authorities, regulators and providers so that any threats to human rights can be picked up and resolved as early as possible” (Equality and Human Rights report 2011:7).

The views of service users are currently secondary to those of providers and commissioners and while registration and inspection services have looked at quality “... the types and quality of home care provision have been shaped by the demands of local authorities, which have negotiated, kept down prices and therefore also continued to depress wages within the sector.” (Glendinning, 2012:298) Money and resources have always underpinned regulation but concerns about balancing risk against choice should not be overlooked. Stevens et al (2011) discuss the tensions between risk and choice and they cite two different accounts of risk. They refer to Boyle’s work (2008) which highlights the need for risk management when planning activities with older people in care homes and to Beattie et al (2005) who discuss how concerns about risk can limit the choices of service users with dementia. In this latter case, risk, particularly around challenging behaviour and the perceived risk of harm to staff and other service users, meant that non-specialist services were reluctant to work with people with dementia. According to Stevens et al:

“Consequently, choice in social care is constrained by perceptions of the likelihood of people coming to harm through their choices or of the threat that they pose to other people (the public aspect of choice), combined with the degree of power held by care coordinators and social services managers. Furthermore, giving individuals more choice over service use is likely to be accompanied by an increased responsibility to manage the stress and risks of so doing (Clarke et al, 2006). It is likely that those with more social capital, particularly those with active and able family carers, will be better placed to understand and manage this element, which could exacerbate inequalities.” (2011:272).

The important issue of inequalities in care provision is an important one that will be returned to below.

Services are understandably risk averse and in a beleaguered and under resourced sector, agencies are likely to discourage choices that they perceive to be ‘risky’. As noted above, risk maybe understood as the potential risk posed by a service user to staff or others but also relates to the risk inherent in allowing vulnerable people to act autonomously and independently. Recent examples of abuse in care homes

(Winterbourne View and others) have demonstrated the risks to people cared for in residential settings and people cared for in the privacy of their own homes are equally if not more, vulnerable to physical, financial, sexual and emotional forms of abuse from carers of all kinds – formal and informal. Milne et al (2013) carried out a study based in Kent and Medway which considered instances of elder abuse and they found that “... over a half of referrals relating to physical abuse and two fifths to multiple abuse were located in the person’s own home.” (2013:498). These cases of abuse were sometimes long standing and only discovered when outside agencies became involved. The lessons from this study are unlikely to apply exclusively to instances of elder abuse and it is essential that everyone involved in provision of domiciliary care is aware and alert to the possibility of adult protection and safeguarding issues.

The CSCI report ‘Time to Care’ (2006) argues for the importance of strong regulation of the care sector because of this potential for abuse of vulnerable clients lacking an independent voice. The report notes that risk may be related to generally poor standards of care, that the home setting itself makes abuse more likely and they also identify ‘unscrupulous care providers’ as a further possible source of risk (CSCI 2006:111) Developing this point, they note that the standards providers work to may ‘measure the wrong thing or could result in perverse incentives’ (CSCI 2006:112). The CSCI report argues strongly for user involvement as a means of regulating services and records that users themselves thought that inspectors should visit people’s homes. One of the methodologies for regulation proposed by the CSCI was peer review of services using ‘experts by experience’ to interview service users, to develop improved survey questionnaires and to provide guidance for staff on how to evaluate service provision. They explicitly refer to the importance of developing techniques that consider the needs of diverse groups of people enabling the inclusion of people who face communication barriers due to disability or language (CSCI, 2006:112).

Domiciliary services present challenges in terms of how to collect reliable data. The ethical issues involved in assessing and evaluating the intimate and personal care of vulnerable people is complex as is determining what acceptable and desirable care is in the first place. It is always difficult to attribute the cause of problems or indeed successes of interventions and when asking service users to comment on the care they receive, it is possible that they have adapted to and accepted poor care as the

norm and do not consider better care a possibility. This may particularly be the case with groups, including the elderly, who feel grateful for receiving any help at all and who may be reluctant to complain or appear to be complaining. Surveys based on the 'satisfaction' of users may just reflect the gratitude of service users (Commission for Social Care Inspection, 2006) or their fear of losing services and Malley and Netten, (2008), draw on earlier research to argue that people are not keen to report dissatisfaction.

This reluctance to criticise and to speak out may be generational or may be linked to a sense of dependency and vulnerability. In an evaluation of a pilot project on the introduction of a IB/Personal budgets in Scotland, Wilberforce et al (2011) found that older people were the least likely to ask for changes to their services "... supporting arguments ... that a consumerist approach to public service reform can lead to inequalities in the application of choice and 'voice'. This was further compounded by suggestions that older people tended to receive the lowest budget amounts which were sufficient only to meet functional needs." (2011:608) The Social Care Institute for Excellence (SCIE) webpage 'Find me good care' provides accessible information on what service users should expect from their care packages and its list 'essentials' such as Dignity, Safety, Choice and Privacy but, as helpful as such resources are, it is not reasonable to expect the users of care to regulate and quality assess their own provision. The multiplicity of agencies and stakeholders in services makes for further complexity.

A final consideration to make in relation to assessing quality of care is to look beyond the person directly receiving care to consider everyone who is a beneficiary of care. In many cases there will be others close to the service user who could benefit from the service. Such people include friends and family who, more often than not, will be informal carers so are, in effect, co-workers in service provision. In some cases it may be appropriate to involve them in the design of services and this may be particularly the case in relation to palliative care provided at home. Percival et al (2013) suggest that meeting the needs of family care-givers requires sensitivity and consistency and services that are proactive and family-centred. Sufficient time to meet physical and emotional needs of patients and family care-givers will need to be factored in and the service will need to be closely monitored and flexible enough to respond to the family's

changing needs. They emphasise that staff engaged in such services will need to be highly trained to provide high quality care that is technically as well as emotionally proficient.

Evaluating domiciliary care

The regulation of personal domiciliary care comes under the auspices of the Care Quality Commission (CQC) and all service providers have to register with the Commission and comply with the 16 core national quality and safety standards established in the Health and Social Care Act 2008. Inspections are unannounced (250 inspections were made in 2012) and use established evaluation methods which can include calling on 'Experts by Experience' who have used the service or cared for people who have. These standards are included as Appendix 4. CQC specifically regulates *personal* care defined as physical assistance to help a person with eating, washing or dressing, or supporting someone to carry out these tasks themselves; it does not regulate services such as a shopping or cleaning even though, as we have seen, these services done well make an important contribution to well-being.

The EHRC report written in 2011 drew on 1254 organisations and individuals receiving both local authority-funded and privately purchased home care services across England. Gledinning writes that it was:

“A highly critical study ... Around half those submitting evidence were satisfied with the home care services they received, particularly the professionalism and reliability of staff; the quality of relationships with staff; and the fact they had some choices over the tasks undertaken by home care workers. However, many other instances of poor quality care were reported, including 15-minute visits from home care staff which did not allow even basic personal care needs to be met; lack of control over the timing of visits; neglect of service users' basic personal hygiene; poor staff awareness and training; and a failure to respect older people's dignity and privacy.” (Glendinning, 2012: 297).

In 2013 the CQC carried out a similar study examining 5 essential standards of quality and safety (chosen from the 16 mentioned above) collecting information from 4,600 people (carers, users, services providers and commissioners) including 738 people in

their own homes. They found much good practice with agencies effectively evaluating the quality of the services they provide but found that staff are still not always well trained, especially in relation to dementia, and that there are many unresolved management problems such as coordinating visits requiring two care staff, inconsistencies and lack of continuity of care. The importance of stability and continuity of care provision was highlighted by Scourfield (2006) and staff reported to the CQC that they did not always feel supported by management. The report makes recommendations in relation to the following areas of poor practice:

1. Late and missed visits,
2. Continuity of care workers,
3. Supporting staff
4. Care planning
5. Safeguarding and safety.

Recommendations in relation to these areas chiefly point to the significance of these different areas of practice and stress that it is important that provision improves in these areas. For example in relation to 3 above, one recommendation is that “New staff should not be placed in the position of starting work without being given a full induction according to national standards.” (CQC, 2013:44) However, there seem to be few sanctions and the report lacks bite even though the CQC has the power to enforce change and to suspend or cancel providers’ registration and to prosecute.

Conclusions and recommendations from the literature reviewed

There is a general consensus in the literature that domiciliary care needs to be actively inspected and that relying on surveys is not enough. According to the Equality and Human Rights report of 2011, “Too much reliance is placed on self-assessment of quality by care providers and more could be done to allow the unconstrained voices of older people to be heard by local authorities, regulators and providers so that any threats to human rights can be picked up and resolved as early as possible” (2011:7).

In addition, critics point to the importance of care relationships and to how the current structure of service provision affects its quality. Two reports on poor care provision,

the Pearson report (Commission on Dignity in Care, 2012) and the EHRC report 'Close to Home' (2010) focused on the importance of the care relationship but neither advocated inspection or reassessment of structures. According to Lewis and West "...both reports are groping towards the importance of the care relationship, but neither pays sufficient attention to the position of care workers, for whom adequate investment in, and regulation of training, as well as regulation of practices regarding registration, hiring and working conditions are crucial." (2014:16).

Further to this, Rubery et al (2013) study of commissioning practices showed that commissioning was not addressing the effect that poor employment practices have on care. They write:

"... the need for commissioning to promote better employment practices among independent providers is still overlooked. Improved quality of human resource policies among independent sector providers is in our view a precondition for long-term improvements in social care." (Rubery et al, 2013:434).

Cost and resource scarcity have had a major impact on services and "Overriding budget constraints, volatile national and local policy priorities, low trust relations, and an unwillingness among national providers to raise employment standards locally all limited the influence of local commissioning on actual practice." (Rubery et al, 2013:419).

Providing safe and caring domiciliary services *is* possible and while they are necessarily complex to provide, it is essential that they are fit for purpose as they have the capacity to keep people active and engaged in wider society. They can rehabilitate people who have had periods of dependency and they can protect and support the most vulnerable in society:

"A quality service from a user perspective is one which delivers the outcomes users are seeking, both in terms of specific aspects of quality of life (such as personal cleanliness, ability to move around freely both in the home and outside, parenting one's own children and accessing meaningful activity and social participation) and also in terms of the important aspects of process (enabling people to have control over their lives, being treated as valued human beings with legitimate needs, being able to choose when to have, and not to

have, assistance in relation to their personal goals and preferred ways of living)." (Vernon and Qureshi, 2000:273).

The UK, and in particular England which is the focus of this study, are socially unequal and there is arguably a widening gap between richer and poorer. It remains true that some people will get better care in at home or elsewhere, because of their social capital, their financial and cultural resources and because of the nature of their disability. Social capital may mean that one person, independently or with their advocates, will be able to express their needs more clearly or forcefully than others. Some will have a greater sense of entitlement and will push for higher levels of support. Still others will fit easily into social categories that attract compassion while others will suffer from disabilities that are stigmatised or are less easy for carers and the public to recognise or sympathise with. Mental health problems may fall into this latter category as may some disabilities that may be viewed as self-inflicted or the result of lifestyle choice. Some people and communities may also be denied equal access to social support, for example some migrant communities who are assumed to live in extended families and to 'look after their own'. More recent migrants may be excluded because they lack knowledge of what help is available and cannot communicate easily with local authorities. Yet other groups, for example, gays, lesbians and transsexuals may be reluctant to accept support and open their homes to people who they fear may judge their lifestyles.

Co-production is a way of improving services in the home and elsewhere as it attempts to break down the barriers between the numerous participants in 'producing' care. These participants include first and foremost the service users and their close family and friends, the individuals and organisations that provide the day-to-day care, specialist care providers and advocates as well as social workers, commissioners and others, including the taxpaying public. According to SCIE, co-production can be broken down into the following elements:

"... co-design, including planning of services, co-decision making in the allocation of resources, co-delivery of services, including the role of volunteers in providing the service and co-evaluation of the service." (SCIE, 2013:8).

Co-production can help make the best use of scarce resources, deliver better outcomes for people who use services and carers, and ideally build stronger communities and that open up the benefits of citizenship to excluded people. It can also challenge to perceptions of old age and disability through recognition of their resources and capacity to contribute (Tanner, 2005). Another idea to improve the quality and equity of health and social care is the use of more qualitative and discursive methods of evaluation. Perreault (2010) has suggested developing panels of expert service users to monitor the performance of service providers and Jenkins suggests augmenting surveys and combining qualitative with quantitative methods with the aim of going beyond measures such as Quality Adjusted Life Years which attempt to quantify a qualitative event (Jenkins, 2001:96). Kathryn Ellis (2004) argues for a more positive use of Human Rights legislation which she sees as often just reinforcing defensive practice. Instead she maintains that fostering a human rights culture in social care could encourage progressive change in services.

Equitable and effective domiciliary care has a social importance beyond the benefits to the individual receiving care. As we have seen, domiciliary care can maintain the autonomy of people whose health is impaired and can allow them to have useful, satisfying and productive lives. Good care reduces the burden on informal carers and keeps people independent and away from costly acute services. Deeming has written that “Governments around the world – including the British government – are increasingly concerned about the quality of life and the environment in which we live, as well as the traditional measures of GDP and economic growth that help to define living standards in society (Deeming, 2013:542) People requiring support to live independent lives in their own homes are amongst the most vulnerable members of British society and unsurprisingly they experience lower than average levels of subjective well-being. Deeming continues:

“There are clear links between age and health in the data as expected, but poor health also interacts with other forms of social and material circumstance, such as unemployment, low income, low ‘social class’ and self-rated disability (Clark and Oswald, 1994). Clearly, social policy has to address this great complexity and diversity.” (2013:560).

The personalisation agenda and an emphasis on choice has great potential to promote the subjective, as well as objective, wellbeing of the recipients of care services at home. Concern for matching care provision to the individual needs and desires of those cared for is essential to avoid waste and to make care packages acceptable to those benefitting from them. This review of literature has shown however, that 'choice' can only be a reality when the services offered are able to provide the sort of services clients require. Choosing between being washed and fed or having a friendly chat with the only person you may see that day is no choice at all and funders have to accept that cutting visits down to the bare minimum in terms of time and activity invalidates the whole experience and undermines the caring relationships that are essential to these services. Relationships are at the heart of care in the home and elsewhere and accordingly commissioners of services need to ensure that service providers have them in mind when they train staff and manage and monitor the services they provide. In resource straitened times, services that meet all the needs and desires of service users and their advocates will not be fundable so everyone involved needs to make difficult decisions and approach the use of public funds realistically. In making these difficult choices, concerns for basic equality and social justice mean that the users, defined broadly, of these essential services should have a least as much of a role in determining and shaping them as service providers and commissioners.

In conclusion, our literature review has highlighted some of the most pressing challenges facing providers and recipients of domiciliary care. Financial pressure on publicly funded services is a major challenge that is only likely to intensify and successive governments' have looked to private sector organisations for a solution. These organisations themselves struggle to retain, train and pay for staff with the skills needed to provide care services. Safety and safeguarding issues are at the heart of service provision and caring relationships and maintaining high standards in services in private homes requires constant and sensitive monitoring. Monitoring and service evaluation needs to be ongoing and proactive and must ensure that care is provided safely, to a high standard and, importantly, in a way that the service users are happy with.

HOME CARE IN ENGLAND – THE LOCAL VERSUS THE NATIONAL CONTEXT

Helping older people to live independently at home is recognised in Bexley's Joint Strategic Needs Assessment (JSNA, 2014) as a key priority. However, the JSNA highlights that the number of older people, aged 65+, who are helped to live at home has declined since 2007, at which point they were significantly above national levels, to below national levels in 2009/10. Such decline is consistent with national trends and data from the UK Home care Association (UKHCA, 2015) which demonstrates that the number of people in receipt of home care has decreased nationally, whereby there has been a steady decrease of older people receiving public funding for social care services in England since 2005/6 (Age UK, 2014). This is despite the increasing ageing population, with the largest proportional increase expected in the very elderly, aged 85+, to increase by 46% by 2021 (Age UK, 2014; JSNA, 2014). This group is the group most likely to require care.

The decrease in people receiving home care is largely attributed to tightening eligibility and access criteria. Eligibility thresholds for services were raised in 2010 for many boroughs and according to the Personal Social Services Research Unit (PSSRU), approximately 95 per cent of local authorities, including Bexley, reduced the number of older people receiving services in the period of 2005/6 to 2012/13 (UKHCA, 2015; JSNA, 2014). According to the UKHCA (2015), the total number of people in England to receive domiciliary care funded by the state in 2013/2014 was 468, 725. This number includes people with short term packages as well as terminated contracts and it is estimated that 389,538 people at any given time is in receipt of domiciliary care services.

Notwithstanding, there has been a small but steady rise in the number of people in Bexley in receipt of home care since 2011 from 781 in 2011 to 938 in 2013, currently totalling around 1100 people (JSNA, 2014). At the same time, the number of referrals, assessments and packages of care decreased by 33 per cent between 2009/10 and 2012/13, whilst completed assessments rose during the same period, from 2,750 to 3,075. This is largely attributable to the ageing population in Bexley, the rise in people aged 65+ has increased significantly between 2001 and 2011 and the trend is

expected to continue (JSNA, 2014). Although the numbers in Bexley are in line with national average, Bexley hosts the third largest population of over 65+ amongst London Boroughs, and it is expected that by 2021, there will be a 15% increase in the over 65+ in Bexley, from 37,200 in 2011 to 42,834 on 2021. Moreover, a significant proportion of people aged 65+ live alone (61%) and with this figure expected to rise, there will be even more demand to support people to live at home (JSNA, 2014).

According to the UKHCA (2015) the number of hours of care delivered in England has plateaued since 2009, which is largely attributable to the tightening of eligibility criteria. The UKHCA (2015) estimates that in a typical week, 3,558,995 hours of home care are delivered, which is a decrease from 3,837,819 hours in 2011. In Bexley, the local authority currently commission approximately 12,000 hours per week for long term care and re-ablement for its older population (2015). Moreover, information presented in Bexley's JSNA (2014) suggests that the number of hours per service user is increasing and the report suggests this demonstrates needs are changing and becoming more complex. This may be influenced by the higher eligibility thresholds, coupled with the ageing population, as older people are likely to have substantial and complex needs, thus requiring additional time from care services.

Information obtained through the Freedom of Information right states that Bexley's budget for Adult social care by private domiciliary care providers is set at £6,955,000 for 2015/16. In England, the expenditure on domiciliary care provision in the financial year 2013/14 was £2.9 billion, which represents an increase of 1% from 2012/13, but is still below the expenditure in 2012/11, which was £3.12 billion. Additionally, in England, the average price paid by local authorities for domiciliary care in 2013/14 was £13.77 per hour, whereas Bexley has a set a fixed rate of £12.60 per hour for private home care providers.

In March 2015, there were 8,186 home care providers registered with the Care Quality Commission (CQC) in England, of which 25 are registered in Bexley (UKHCA, 2015, Homecare, 2015). Currently, approximately 92 per cent of all home care providers in England are delivered by the independent sector, with the remaining 8 per cent delivered by the statutory sector (UKHCA, 2015). This reflects an ongoing trend where the independent sector is responsible for a growing percentage of home care delivery.

The percentage of home care delivered by the private sector in Bexley was unknown at the time of this study.

METHODOLOGY

Due to the exploratory nature of the study, a qualitative approach was adopted to allow the in-depth investigation of narrative accounts of people receiving home care. The main method of data collection was the conduct of individual oral history interviews. All interviews were undertaken by Healthwatch Bexley staff who were trained on interview techniques by academics at Canterbury Christ Church University. Whilst the benefits of undertaking Oral History research are well documented, it is worth reiterating some points here (Thompson 1978; Thompson, A, 1998, 1999; Frisch 1990; Klemptner 2000, Palmer, 2010). The practice of oral history techniques is the collecting, recording, interpretation and preservation of historical information from observers and participants in that past (Thompson, 1978). The nature of oral history means that frequently some of the most interesting information to emerge from oral history techniques is often completely unexpected. These contributions, together with oral history's ability to capture and preserve information and provide great insight into the ways in which relationships between public and private, personal and political are continually negotiated, illustrates some benefits of this method of inquiry (Rogers *et al* 1999). This method can reveal how individual values and actions shaped the past, and how the past shapes present-day values and actions and how people use it to interpret their lives and their surroundings (Frisch 1990, Palmer, 2010). It is the perceived disjunction between individual experiences of Home Care and the (few) representations offered in wider discourses, the media, and by traditional research disciplines that provided the motive for oral history research.

A total of 26 semi-structured interviews with recipients of home care aged between 55 years and 102 years were undertaken in the London borough of Bexley between May and September 2015. Diversity was reflected in factors such as gender, age and disability. Participants were contacted through the London Borough of Bexley. Although attempts were made to engage with non-English speaking participants, for this particular study all interviews were conducted in English.

All interviews were undertaken in people's homes and followed a life story method where individuals were encouraged to freely discuss issues they felt were important to them. The interviewer took care to be sensitive to topics initiated by the narrators and to allow the interview to proceed in as naturalistic manner as possible. Interviews were audio recorded with participants' written consent and the digital recordings were transcribed for a thematic analysis. The research team considered key ethical issues and dilemmas including the complex issues of insider and outsider status, lack of familiarity with the research process, issues of informed consent and safeguarding anonymity; these issues were addressed in the invitation to participate, design of the interviews and process of data collection. Ethical approval was obtained from the Research Ethics Committee of the University of Kent, UK.

Interviews varied in duration but lasted on average for one hour and all interviews were undertaken in participant's homes and at a time which was convenient to them. All Interviews were digitally recorded (with the participants' consent) and verbatim transcriptions of all interviews were made. Nine interviews were conducted with a family member/ carer present or responding on behalf of care recipient.

For this study, non-probability sampling was undertaken which refers to situations where the research cannot or does not sample the whole population and therefore cannot claim representativeness (Jeffri, 2004; Denzin and Lincoln, 1994). As a result, such sampling techniques severely limit the potential to generalise from the findings of the sample to the wider population.

Demographic data

Of those interviewed, ages ranged from 55 to 102, with a mean age of 80 years. 3 participants stated they were single, 11 widowed and the remainder (n=12) were married. 18 were female and 8 male. All those interviewed described themselves as British and lived in various parts of the Borough, with Belvedere, Bexleyheath, Welling and Sidcup being the most prominent areas.

Ethnicity	
English/Welsh/Scottish/Northern Irish/British	26
Total	26

Gender	
Female	18
Male	8
Total	26

Marital status	
Single	3
Married	12
Widowed	11
Total	26

Area	
Belvedere	4
Bexley	1
Bexleyheath	7
Blackfen	2
Northumberland Heath	1
Sidcup	6
Welling	5

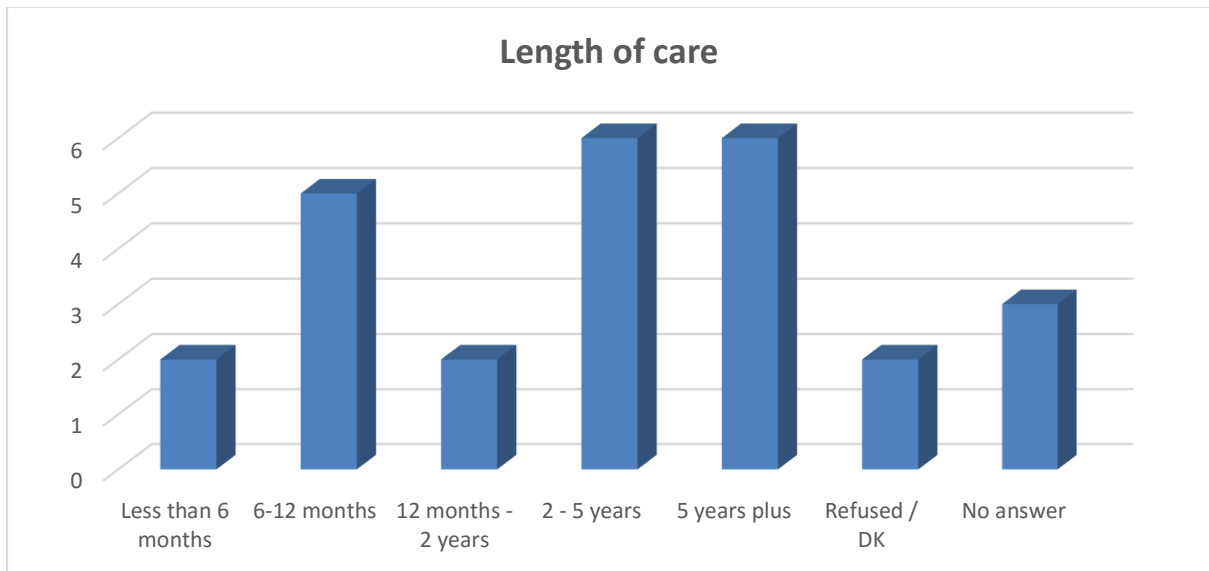
Only 3 participants had not reached pensionable age and none were currently employed. All identified as White British. The majority of respondents (N=20) lived in their own home with no mortgage.

Housing Tenure	
Own home with no mortgage	20
Owned sheltered accommodation	1
Rented from council or housing association	3
Rented privately	2

Many participants reported multiple health concerns. Mobility problems were cited as the most common reason for receiving care (N=12), followed by Dementia; heart problems; arthritis; Multiple Sclerosis; and sensory impairments. Participants also reported disabilities following stroke, or complications resulting from operations, as well as conditions such as Parkinson's or Down's syndrome. Only one recipient of care told us they had been diagnosed with a mental health condition.

Disability	
Age related	1
Amputee	1
Angina	1
Arthritis	5
Bipolar	1
Bladder problems	1
Blind	1
Brain Haemorrhage	1
Cancer	2
Deaf	1
Dementia	3
Down Syndrome	1
Heart Attack	1
Mobility	12
MS	3
Osteoporosis	1
Parkinson's	1
Partially sighted	1
Speech	2
Stroke	3
Vascular	1

The length of time respondents had been receiving care ranged from less than 6 months to 15 years, with a mean of 3.5 years, although some interviewees were unsure of exact timings. Most respondents received at least one care visit daily, with just 3 receiving fewer than 7 visits per week.



Of those interviewed, 22 respondents told us that their home care included help with showering, bathing or washing. 15 received help with dressing; 13 told us they had help to prepare and/or consume meals or drinks. A total of 10 recipients of Home Care told us they had help to get out of bed and/or prepare for bed whilst 7 interviewees told us they received help with toileting or changing incontinence pads. Four participants told us they receive help with skin care, such as applying creams, 3 received help with medications and dressings/catheters; 2 told us they have help to use a hoist to transfer between bed, chair and bath; and 2 told us they have help with housework from care workers (some others told us they paid for help with housework privately).

Recruitment

A list of up to 500 names accessing Domiciliary Care in Bexley were put into random order by the London Borough of Bexley and all residents on the list were sent a letter and study information sheet, inviting participation in the study. Carers' views were incorporated in the design of information sheets and consent forms. Data was extracted using a semi-structured topic guide as a framework.

Data Analysis

Data analysis followed the 'Framework' approach (Ritchie and Spencer, 1994) a content analysis technique widely used in qualitative research. Each of the transcripts

was read and re-read by the author, following which a coded framework was devised. Thematic categories were applied to each transcript and then 'charted', a process by which key points of each data were summarised and documented on a spreadsheet matrix. Thus a set of categories were obtained which described the main themes arising from the interviews. The author (DP) worked collaboratively with colleagues with Canterbury Christ Church University who 'pair coded' the data. This pairing forced a level of communication and understanding of the data that may not be otherwise achieved.

The findings and discussion section has been merged due to the nature of the research findings. The quantitative findings are supported by qualitative and informative research with individual 'voices' narrating stories, expressing opinion, and therefore contributing to the on-going discourse within the field of Home Care and health care studies in general.

FINDINGS

Summary

Users of domiciliary Home care were found on average to be generally “very satisfied or satisfied” with the home care service. However, the majority did highlight issues with the service, most commonly around inflexibility, unreliable staff and the frequency and duration of visits by care workers. Improved communication and continuity of care were indicated as areas meriting particular attention. Generally, recipients of care were more satisfied with the service than family carers with an active caring role, who were more likely to express criticism of services. Recipients of care were most likely to criticise services for lack of good time-keeping and lack of regular carers. The majority of recipients of care reported positive experiences of interactions with (regular) carers. Negative experiences were related to lack of training and motivation; lack of time and regularity; and unmet social, emotional and rehabilitation needs. Care recipient recommendations centred on two main areas: reliability and consistency of timings (n=6); scope and quality of care (n=6). Recommendations also included being given greater choice, more time to talk, consistency of carer and listening to clients more. Three respondents were neutral or ambiguous in their recommendations, while 7 respondents didn’t identify anything currently in need of improvement.

Overall quality of Home Care

Overall satisfaction with services on a scale of 1-5 (with 5 being the most positive) was 3.9 (average score). Table 2 below summarises how participants rated the overall quality of the care they received:

Table 2: *How participants rated overall quality of care they received*

Very Poor	1 (3.7%)
Satisfactory	4 (15.4%)
Good	7 (27%)
Very Good	10 (38.5%)
Mixed views*	4 (15.4%)
TOTAL	26

* Some verbal responses were given an approximate score by the interviewer (very good and poor)

81% of respondents rated the quality of care they received as satisfactory or above. However, as discussed below, many of the people interviewed who rated their care as better than satisfactory went on to express dissatisfaction with particular aspects of the service

“I don’t complain very often, I try not to.”

Studies by the Healthcare Commission in 2005 and 2007 acknowledged that older people have a tendency to respond more positively to questions around the quality of their care, which was suggested to be linked to lower expectations, gratitude, or anxieties about how negative feedback may affect their care provision. This propensity in older people was acknowledged by Bowling (2002), who suggested that their inherent gratitude for health care may reflect a feeling that they have access to better treatments and greater agency in their care than generations before them. Bowling urged researchers to look beyond satisfaction measures to the in-depth responses of older people, when asked about their care.

Qualitative findings

Summary

The qualitative findings revealed a far richer picture than the simple ratings of care data. The responses to our questions provided an invaluable insight into the experience of those receiving care. This section will outline the main themes including home as a changing space, the organisation of Home Care, the carer relationship, lack of consistency, training, stress and pressures and unmet needs that developed throughout the interview process; these reflected the priorities and concerns of both the carers and their families. It is important to note that the focus of the interviews tended to be more on the issues or concerns that the recipients thought needed attention/improvement and although it was made clear that the interviews were not a direct route to improving their service it is understandable that, at least to a certain extent, recipients used the time to air such grievances. However the context of the interviews was most definitely one of positive gratitude for the service, even with all the possible and actual concerns and issues expressed throughout.

Care recipients and their families described their care packages in detail and most placed high value on the help they received, with particular reference to help with personal hygiene and dressing. These two basic elements were given a high priority in relation to self-esteem and confidence providing recipients with the opportunity to maintain their normal daily activities and maintaining a positive self-image. Every one of the participants in this research expressed the wish to have the opportunity to remain for as long as possible in their own homes, but with effective tailored support. Echoing previous research (Angus et al 2005; Gibson et al 2012), respondents spoke of their strong preference to remain in their home, and the majority felt that home care had enabled them to do so. However, respondents also spoke of the difficulties involved in negotiating new boundaries within their home, as private spaces became the working environment for another, potentially unknown, person. Some respondents found it difficult when the aesthetic quality and familiarity of their carefully created environment was altered by care workers, including the introduction of unfamiliar languages into the home. They also spoke of the restrictions that aging and disability placed on their living environment as parts of their home, and equipment within it, become inaccessible. Care recipients were also challenged by changes in how they viewed their bodies, as they too became a space to be shared with care workers, sometimes of the opposite gender. Although many respondents reported that they were treated with dignity and respect, some respondents' spoke of feelings of vulnerability caused by others having power over how their bodies were treated and presented.

Many care recipients praised their care workers, particularly when a positive relationship had been enabled by consistency of carer and empathic interactions. Recipients of care valued friendliness, empathy, individual care, humour, experience and dedication. Shared laughter was seen as a measure of relationship strength, and was particularly reassuring to care recipients' families. For many respondents, care worker visits were the only regular human contact they received and consequently felt, when done well, the contact enhanced their quality of life. However, many respondents lamented the lack of personal interaction and deference to their preferences, particularly when care workers were not familiar to them. Lack of consistency of care worker, attitude of care worker, or language barriers were cited as reasons for not benefitting from a positive relationship with care workers. A small

number of respondents felt they did not want to build close relationships with care workers.

Many respondents felt they had not been fully involved in the organisation of their care, although experiences of pathways and degree of choice over care options were mixed. Transition periods, either from hospital to home care or when care providers were changed, were highlighted as potentially disruptive and anxiety-provoking, particularly when lack of communication led to lack of clarity over what to expect from the process. Most respondents perceived their level of influence over the type and level of care they received to be limited. Personal funding constraints along with perceived resource constraints were also seen to affect level of choice.

One of the main criticisms voiced by care recipients and their families was inconsistency in care schedules. Some respondents felt they did not have care visits at times that suited them, while other said that care workers often did not come at the same time each day, which made it hard for both them and family members to plan their days. Care worker lateness was seen to have a significant negative impact on quality of life, as recipients of care reported missing out on social activities, not having sustenance or help to get to the toilet / change incontinence pads when needed; or not having other needs met due to shortened visits. Some respondents reported care workers not arriving at all, with one participant talking about how she did not have a care visit for 7 days because her care worker was on holiday. She stated that she had not been informed and nor had a replacements been sent. Care worker lateness was reported to be a more frequent occurrence on weekends.

Care recipients reported diverse attitudes towards irregular care timings, from sympathetic to very upset. Some respondents showed understanding for care workers who were delayed by emergencies or travel problems, blaming care providers for not allowing staff enough time, while others sympathised with the care companies, who were perceived as being let down by staff sickness. A common plea was for better communication between care companies, care workers and recipients of care with regard to delays. Where flexibility was shown in the way and time that care was offered, this was much appreciated. Another commonly cited problem was lack of carer regularity, which was also said to be worse at weekends. Care recipients said

this interrupted the establishment of good relationships with care workers, shown to be an important contributor to quality of life. Some respondents also reported frustration as they felt that with each new care worker came the need to explain their preferences, routines and the location of necessary items. Recipients of care also highlighted what they perceived as a lack of training in some care workers, particularly with younger or less-experienced care workers. Some felt that knowledge or skills were lacking, while others felt that some care workers lacked genuine commitment to providing good quality care. Respondents noted that poor quality of care could be exacerbated by time pressures and low pay, perceived as leading to high staff turnover.

Unmet care needs were most frequently identified in the areas of social support (isolation and loneliness) and participants talked about the benefits of, and improved quality of life from individual one-to-one sessions, having a warm meal or engaging in particular activities. Many respondents reported feeling lonely and/or isolated. For some recipients of care their home care gave them a break from isolation, where for others, loneliness was seemingly reinforced by care workers who did not engage with them, or were seen to lack warmth. For many care recipients, disability or frailty made it difficult to leave the home to build or maintain social networks, and the time limitations of support in the home meant that only basic physical needs were met and meaningful activities were not supported. Time constraints were also cited as a reason why certain tasks were performed by care workers, rather than by care recipients with the support of the care worker. For some, this exacerbated feelings of helplessness, with care recipients lacking agency in actions carried out within their own homes, or to their own bodies. This finding was not however universal with many respondents praising their care workers for respecting their wish for independence and encouraging them to do things for themselves where possible. Lack of enabling equipment within the home was also noted for some recipients of care, resulting in a greater reliance on others to perform tasks or a reduction of mobility and functioning.

In relation to carer family members most expressed feelings of emotional isolation, exhaustion and helplessness, this varied in degree depending on the level of care required. The extent of dissatisfaction was unsurprisingly linked to the successful functioning of the care package their relatives received. Whilst some family members

felt supported by the care workers involved with their family and reported incidents of emotional support and encouragement as well as practical support in terms of practical information, others were not as positive. In these instances respondents spoke of the impact of carer lateness and unmet care needs inevitably putting a greater strain on them, sometimes resulting in them missing out on other activities, such as employment or social support.

The recipients of care interviewed for this study usually felt they knew where they could turn to with complaints, although many expressed a reluctance to complain. Some said that their reluctance was due to not wanting to get people into trouble, where others reportedly feared a worse consequence for themselves. For those who had voiced complaints about their care, outcomes ranged from high satisfaction to dejection. Some of those who made complaints felt their grievances were neither listened to nor taken seriously.

Care recipients were asked how they felt the service they received could be improved. The main areas for improvement were noted as time-keeping and quality and scope of care. Some participants stated that they felt there were no improvements to be made, while others were ambiguous in their response.

The section below presents the main findings in more detail, with direct quotations from interviewees for illustration.

Analysis of Themes from Interviews

The role of Home Care – summary of care received and potential difficulties

“In the morning I have a carer that helps me, because I hoist myself but she helps me in the bathroom and getting dressed and washing up a few things, makes me a cup of tea and a bit of breakfast. In the afternoon carer does the washing up for me, makes me a cup of tea and does whatever, makes me a sandwich or a bit of food and what not.”

The quote above provides a very typical description of the type of daily care the recipients of this study received. The primary forms of care experienced by the respondents reflected mostly their practical needs but with some consequential emotional needs. Ordinarily their home care tasks included:

- help with showering, bathing or washing, dressing,
- preparing meals and drinks,
- help to get out of bed and/or prepare for bed,
- help with toileting or changing incontinence pads,
- help with skin care, such as application of creams,
- help with medications and dressings/catheters,
- help to use a hoist to transfer between bed, chair and bath; and
- help with housework.

The quantitative approach elicited positive responses when discussing satisfaction levels relating to domiciliary care where typically respondents said they were “very satisfied or satisfied” with the home care service. However, when they began unpacking their experiences their responses reflected a more complex set of expectations and experiences moving beyond simple expressions such as being ‘generally happy’ with their home care service. These responses reflected some of the problems and inconsistencies experienced with the service they received. The primary concerns related to inflexibility, unreliable staff and the frequency and duration of visits by care workers. Improved communication and continuity of care were indicated as areas meriting specific attention. Some people commented on the limitations of their home care service, such as short duration of visits, little continuity as regards care staff and inconvenient or irregular call times. They felt that while the care they received did cover basic needs, a lot more support was needed in order to

achieve a good quality of life. One recipient of care said that they did not see the relevance of care to facilitating engagement in family and community life:

“Does the care enable you to be part of a family and a community?”

“Well not the caring system, that’s irrelevant to the caring system really.”

Some care recipients talked of the impact of time limits on their individual preferences or choices, for example a desire for baths over showers not being facilitated due to the short length of their care visits. One interviewee, who felt she did not always have enough care time, explained that often such preferences are grounded in more serious concerns. For her a bath was not just a means to keep clean, but also to ease the pain and stiffness associated with an inflammatory condition:

“I need to have a bath every day because that helps with one of my conditions called Polymyalgia rheumatica and it helps to take away all the hurts in my body. I’d love to stay in there longer but it’s been a bit difficult even for me to get that bath done every day because of the hours you are allowed to have this that and the other.”

Another important aspect of care with which some interviewees received help was dressing for the day, and getting changed at night time. Respondents told us how help with dressing allowed them to socialise and participate in meaningful activities:

“Well if I didn’t have the care I wouldn’t be able to do the things I do, I wouldn’t be in there partaking quizzing or go down for anything or even go down to chat if I didn’t have the care because I can’t dress myself. I’d be in my night clothes all day long or be frustrated which is not good is it, raises your blood pressure.”

Many respondents also described the impact of late arrival of care staff, which for some meant having to miss out on pre-arranged social activities, because they felt they were not dressed appropriately to see visitors or attend regular religious worship. One interviewee also explained the negative impact being ‘unprepared’ in terms of appropriate dressing had on her sense of self and self-esteem:

“Because it gets you stewed up if you’re lying there and you’ve got, say a chiropodist coming and you’re lying there and you’re not dressed or anything, I feel terrible. I like to be dressed when people come in.”

The impact of timing, both in terms of appointment times and duration is discussed in more detail later in this paper.

The reference to self-esteem was a common theme throughout many of the interviews relating to how care was experienced and what care was given. Self-esteem was most frequently mentioned in relation to personal care. Some participants told interviewers how help from carers with their appearance could provide a boost to their self-esteem. This was cited as a factor both in terms of basic cleaning and hygiene but also in more subtle ways relating to simple friendly tasks such as helping them choose an outfit they felt good in, or helping them maintain self-grooming habits, such as varnishing nails.

Help to prepare drinks and meals was also a large part of the care tasks described by the interviewees. For some, cooking was an activity they had enjoyed and missed. In particular, one 80 year old interviewee told us how hard she had found it not to be able to cook anymore:

“um I can’t sort of stand long enough for the discomfort below for to say cook a meal ourselves – we have Wiltshire farm foods things like that. Where I always cooked every day, we were not ones to have takeaways because I love cooking and so I say a complete change around but we’ve come to terms with it.”

Another care recipient, herself a former cookery teacher, spoke of how her inability to cook for herself had also forced her to change her daily routine and preference for a cooked mid-day meal. The care procedures did not allow for such individual preferences as time was not necessarily allocated for lunchtime visits with a cold lunch, such as a sandwich, being pre-prepared by care staff during their morning visit. It was apparent during many interviews that this loss of autonomy and control was something that many respondents struggled with but seemed to have accepted that it was “the way it has to be now.”

The following section has been divided into the dominant themes as they emerged during the interviews:

- Home care: why it is needed – changing realities

- Transitions: home as a changing space – adaptations, the first step
- 'Home': no longer a private space – conflicting feelings
- The organisation of home care choice: the next step – influence on type and level of care
- The carer relationship – positive carer interactions
- Professional distance? – the absence of close carer relationships
- Cultural expectations – communicating need
- Logistical implications – timings and lateness
- Lack of consistency – carer regularity
- Lack of training, stress and pressure – barriers to good care
- Unmet needs: loneliness and isolation – facilitating community involvement and independence
- Transport issues – feeling trapped and isolated
- Home care as respite for family carers
- Feedback and complaints
- Care recipient recommendations

Home care: why it is needed – changing realities

“Does the care provided help you remain in your home and do what you want to do?”

Well yes, yes well they, you know they do yes yes. Cause I, I mean, the whole point is for us to be able to be at home and not have to be in care.”

Home care provision can improve quality of life and the ability of people to maintain living standards at home in later life (Ryburn, Wells and Foreman, 2009), and is the preference of most care recipients and their families (Angus et al 2005). Statistics from the Mental Health Foundation (2015) testify that depression affects twice as many older people in care homes than living in the community. These outcomes are also true for other sections of the population where residential care is an option, for example in Gibson and colleagues (2012) study residential care was referred to as the “worst-case scenario” for disabled people (p. 214). The concept of ‘care’ is a complex issue; within research literature it is unclear as to whether the practical application of a system of care at home seeks to promote independence or to address dependence. In practical terms the difficulty of determining the reasonable limits of care that should be available for people at home is multifaceted. Care cannot be fixed, varying both in the context of individual needs, risks and the practicalities of providing care. It is problematic when trying to understand how an older person, ‘chair dependent’, incontinent and significantly confused from intermittent carer visits and significant periods of isolation, benefits from being at home. In its opposite it is also difficult to comprehend how it can be acceptable for a person to be forced to move from their home simply because relatively low levels of home care are no longer available.

The context for any discussion concerning appropriate and desirable home care is the process of aging. It is an unforgiving and unrelenting inevitability involving the deterioration of physical and cognitive functioning. This is then compounded by the denial of certain privileges such as driving and employment, and the increasing frequency of the separation and/or deaths of friends and loved ones. Any combination of these tragic occurrences inevitably depletes the individual’s resources for social support and personal independence and may lead to their need for long term care. As

discussed previously in the literature review, Home Care has traditionally aimed to alleviate some of the more necessary new requirements evolving from the aging processes. It typically involves the provision of various forms of help at home enabling older people to preserve a dignity and independence through assistance with cleaning, laundry and shopping or perhaps help with eating, having a bath, hair washing and companionship. Over time this has increasingly meant full “care at home” with a vague intention of meeting all the needs of older and disabled people choosing to stay at home rather than having to go into residential care.

The experience of the majority of participants resonates with this research and literature in relation to how home care is both perceived and received. It was widely reported by interviewees that Home Care was a lifeline which allowed them to preserve their independence and continue living in their own home. Despite some of the problematic practical realities of administering a home care system that is able to respond to the individual needs of service users, as discussed previously, participants in this research undoubtedly value this service and underlined the vital contribution it makes to their lives. Participants described the care they receive as invaluable because without it they simply could not cope with the basic activities of daily independent living:

“If you didn’t have the carers what would life be like?”

“It would be dire; I would not be able to get out at all.”

In contrast, one interviewee described her experience of residential care, explaining how much happier she felt in her own home, where she could choose what she wanted to do and when:

“They are all just sitting round in a ring. I think at [name of care home] we had one afternoon, we had a quiz afternoon another morning you would go down and they’d do handicraft or something like that but otherwise I would get bored stiff. At home I can do what I like here, I know there are televisions in all the bedrooms, you could have the television on in the bedroom, but here I can do what I like, I want to go and sort a cupboard out I can if I want to sort a drawer out I can do what I like but there you’re sitting there. I just hated it.”

Some interviewees felt that the support provided by their home care worker, but also the reassurance gained from daily visits, enabled them to continue happily living independently in their own home. The majority of respondents said that the help and support they received helped protect their dignity and security (security is discussed further in the next section):

“As I say, I couldn’t manage without it and I’m so lucky to have it otherwise I would have to have gone in to a home of some sort. In a few years I will have to be looking at the homes.”

“It [home care] makes me feel safe to stay at home and I can keep my dignity, not having to feel defeated, like I’ve given up.”

Many people said they would be reluctant to go into residential care. Even those who identified problems within the home care service said they would rather receive care at home than be in a residential setting:

“I know things are worsening and the day might come, I hope it doesn’t, I hope that I depart this earth rather than see myself end up in a care home. I can see that drawing more closer which frightens me. That I don’t want.”

Transitions: ‘home’ as a changing space – adaptations, the first step

“Son: I know but with all the different carers coming in and some of them not announcing themselves or ringing the bell”

“Yes it’s very different but I can’t say that thinking I would prefer to go into a big home because I don’t like lots of people, I tend to be scared of them actually. I’m going to my corner”

The concept of ‘place’ is significant within this research as it allows for an exploration of the private space (home). Participants talked about how their homes had acted as both a reassuring space but also as space no longer suited to their changing needs. Like themselves their homes needed to adapt and change in response to new challenges and circumstances. When considering these adaptations the home was often talked about in relational terms “I’ve changed so it has to change”, “we have to make things work differently now”. The home has now become a place of transition,

the space is used differently and in allowing 'others' (home care services) into the space the relationship between participants and their homes inevitably changes. It is evident that the participants in this research, and their homes, have had to adapt to facilitate interactions and experiences that impact on health and well-being. As discussed previously the over-whelming majority of participants desired to remain in their homes or lamented the inevitability of residential care. However this research provides an opportunity to explore how the participants relationship with their home and their concept of home, has been challenged, changed and significantly what concepts and feeling have endured throughout this time of transition.

The concept of 'place' has changed and evolved both over time and in relation to the theoretical perspective or discipline within which it is being explored. Within social and cultural theory, the most relevant conceptualizations when exploring the experiences of participants are those that define place in terms of social relations and interactions (Smyth, 2005). The anthropological study of cultures and practices has also highlighted the need to understand that an individual's emotional relationship with a specific physical place, in this case the 'home', is created and informed by the social relations and practices which are enacted in them: *'physical territories may be capable of being 'made and unmade' as sacred or meaningful because of the socio-ritual activities enacted there'* (Gupta and Ferguson, 1992). The everyday activities carried out by participants in their homes reinforced their sense of identity and connection to their past and present. These activities may be the simple ritual of making a cup of coffee or dusting family photographs yet they act to reassure and remind providing consistency and stability of being:

"I know things have changed and I can't do the stairs anymore and then there's a seat in the shower, ha ha (laughs), but I know all the sounds and feel of everywhere, I know where I keep things and I have so many memories, I can't imagine not being here."

It is evident that many older people view their home as an important part of their lives, providing fundamental benefits to their health, wellbeing and quality of life The participants in this research evidently have a very strong emotional relationship with their home:

“Because that’s what I miss most of all, walking round in my own home and doing things I used to do because I always used to get my own breakfast, get myself up and washed and lunch, I miss doing that for myself. I miss looking out at the garden because I can’t see that now. We’ve got a lovely big fish pond and I can’t see that.”

This theoretical understanding of the significance of ‘place’ or ‘landscapes’ has emerged within research and literature in relation to the possibility that certain ‘places’ are conducive to health, and recovery (Gesler, 1996; Rosenberg and Wilson, 2005; Smyth, 2005). In concurrence with much anthropological theory, this perspective focuses on both the meanings ascribed to places and the individual experiences of places and potential such feelings, meanings and exchanges can have on an individual’s sense of self, belonging and therefore well-being. This understanding of place is therefore subjective and although much of this literature relates to open or public spaces it also has resonance with the emotional and physical attachment respondents in this research had to the desire to remain in their home. It is evident that the ‘home’ as a meaningful place has a powerful transformative impact on people’s everyday lives (Kearns, 1993):

“It’s just familiar; I know it, you open your eyes in the morning and you know where you are. I feel better here, I’d be all at sea somewhere else, I don’t belong, I’m better here, happier.”

The home and the reality of being surrounded by familiar space, objects and artefacts such as family photographs evidently create an evocative atmosphere for the elderly participants. It includes many different opportunities for remembrance whilst at the same time being expressions of their identity as familiar artefacts are important identity markers and reinforce a sense of belonging.

Many of the participants were housebound for significant lengths of time; often this was as a result of disability or poor health. The substantial proportion of time spent at home meant that the significance of a familiar home environment in supporting their wellbeing was of amplified importance for many respondents. Some respondents spoke of the inconvenience, and sometimes risk, caused by unwelcome changes to

their home environment. One partially-sighted interviewee described the impact of her personal items being moved:

“and I can’t see conventional clocks, I have a couple of clocks that spell out in numbers the actual time and more often than not, they seem to go astray. We had a space in the bed where they could stay permanently and so they didn’t get moved but this didn’t last very long because the mattress changed or something so it wouldn’t sit in there permanently. I’ve got to the stage where I don’t bother normally if I can’t find the clock very quickly I think well you know, do I really need to know the exact time and I just wait and then try and time in about the time radio gives it out.”

Adapting to survive

Petersson et al (2008) produced evidence to show that ageing in place through the aid of housing adaptations fosters a sense of security and belonging among older people that is positive for their wellbeing. Firstly in relation to physical well-being, the necessity to adapt houses to the changing needs of residents is important to avoid an increased risk of falls, a major cause of injury and hospital admission amongst older people:

“I’m not able to get up and walk around and I can’t walk without using that even I walk up and down the hall about 6 times a day I try to do it but because I think I need some exercise and I can’t go out unless somebody takes me out. That’s the only thing about this house, it’s not wide enough for a wheelchair so they have to take me round the back and bring me in the kitchen door.”

“as I can’t get upstairs now. I know we’ve got the chair lift but I can’t get on it. Well I can’t get off at the top, if I got off at the top what would I do? I can’t lift myself into the wheelchair so husband sleeps upstairs and I’ve got a phone and last night I was ill and I had to get him up twice, didn’t I poor soul. You can dose today (laughs) I don’t mind as I kept waking you out of bed. Poor devil I thought I can’t stand it he’ll have to come down and help me.”

Effective adaptations and improvements to the home have quantifiable effects with regard to improved health, well-being and independent living, particularly for those

with chronic conditions (Chesterman, Bauld and Judge, 2001) Secondly in relation to emotional well-being participants communicated that feeling at home in their adapted and modified surroundings was important in helping them to feel safe, independent and secure. To this end home adaptations were found to have a facilitating role and home modifications strengthened the personal and social meaning of home for participants:

“I love it, it means I can still be here, it’s still mine, I needed to get used to it, the changes, but I’m not stuck any more, I don’t have to worry.”

The inability to obtain necessary adaptations was a point of contention and concern for many participants. More than one interviewee spoke of having difficulty in obtaining adaptations to the home which would enable them to remain mobile around the house and provide access to the outside:

“Well we needed our home adapted you see but they weren’t any help at all. I think I waited a good 6 or 8 months for them to put the ramp out there because there was a little ridge there I could get the wheelchair back in. Also we wanted a sliding door put on or something done to the door so that we could get my wheelchair out because it’s such a sharp turn there and we waited and waited and then I went back into hospital and it was delayed again and then when I came back we had it done ourselves, got a builder in.”

“They then come in and they wheel me out and most of these houses have got steps and that really frightens me when they have to go backwards down the steps and it’s really frightening.”

It is evident from this research that the lack of assistive technology or environmental adaptations in the home placed further restrictions on the activities the participants were able to partake in. Some participants were frustrated by sudden changes to care plans that negatively impacted on their ability to undertake certain activities. The wife of a gentleman whose home care was arranged after he was discharged from a hospital where he was treated for a stroke described how her husband’s care plan changed without explanation, meaning he was no longer able to get out of bed:

“[...] about a couple of days before he was due to come home, I’d gone out to a message on the answer phone which is still on there saying that we have

decided that he won't be hoisted which was the original plan that he was to be hoisted into a recliner chair and that he would be nursed in bed full stop. Nobody told him and nobody explained why. Fortunately the hospice lady came round who's lovely and we've noticed quite a few carers saying they can't understand why he's not being hoisted up and sitting in the chair during the day. [...] Well they've all been put on order, the hoist and the recliner chair."

Interviewees also told us that, although essential to their daily needs and activities, receiving care at home and access to basic mobility equipment was often not enough to allow them to fully participate in their existing social networks:

"I used to but I find it difficult now because my shoulders so painful. I've got a big wheelchair but it's too heavy. I've got 2 friends who are obviously my age so they not very strong and couldn't lift a heavy wheelchair, but the girls have bought me one for Christmas which I haven't got yet. It's a light weight one and my friend said she would take me over to Bexleyheath shopping in it. If I can get in the wheelchair and she can lift the wheelchair into her boot, she can't the one I've got at the moment it's too heavy. I'm hoping that I'll be able to get out a little bit more."

Although appropriate and assistive technology was seen as essential to the health and well-being of participants, it was also evident that this forms only one part of their care needs and consideration needed to be given to other necessary elements.

'Home': no longer a private space – conflicting feelings

When the relationship between carers and clients goes wrong the ramifications are potentially very serious. Although, as mentioned several times, most respondents were generally happy with their home care there were examples of when it can go wrong to the detriment of the most vulnerable. Pink, Morgan and Dainty describe the role of the home care worker as a being both "a professional and a guest" (2015: 460) and they therefore needed to negotiate the balance of power this creates. Their (2015) research discussed situations where health and social care staff visiting clients in the home would have to balance their safety with the need to show 'respect' to the homeowner and their 'private' space. An example given was of a nurse who entered

a patient's home and removed her shoes. Although this may seem to be a simple act it was actually the result of much consideration. The context of this decision was an assessment of the risk to herself (e.g. risk of stepping on "sharp or unclean objects" (p. 459)), and weighing this up against the need to protect her patient's carpet and, in doing so, demonstrate respect for their home.

This was not unfortunately the experience for some of the respondents in this research when the pressures of limited time meant that carers were unable to complete tasks or show a level of care beyond the minimum. More than one respondent interviewed for this study felt that their home was not granted the respect they desired, reporting disturbances to the aesthetics of their home which held significance to them (Angus et al 2005):

"Sometimes they leave the kitchen in a terrible state; they leave all the stuff in the sink, not washed."

"Oh yes the carpets a filthy state through the carers I'm afraid. They were going to replace it but they took 2 years and they never replaced."

One respondent in this study exemplified the feeling of vulnerability that can be created when this power balance (Twigg et al 2011) is not skilfully negotiated, especially around intimate care. The stress within which many carers are operating in terms of time pressures can result in unsatisfactory outcomes that need to be given serious attention:

"They are often in such a rush, they can get impatient. They even threaten to leave me half naked in the bathroom and I said you can't leave me like this half naked because I couldn't dress or dry myself."

The invasion of previously private space in relation to bodily functions is perhaps the most sensitive of all the changes discussed by participants and the transition period was also the most difficult to negotiate. The loss of choice and power in relation to decisions concerning the treatment of the body by at least one professional was difficult to manage for some participants. The son and carer of one recipient of care in Bexley spoke of how care workers had seemingly made choices on his mother's behalf about how and when her body was exposed to others (including himself):

“I was breast fed and I have seen more of mother’s naked body in the last 18 months than ever before. She’s had her private parts seen by more strange men than ever before but I often come in and find that they’ve left her immediate part covered up by something or other. But they often do lay her completely naked when I’m coming in. But there are men about in this business.”

Another care recipient, who uses baths to help manage her pain, told interviewers that there had been occasions when she had foregone a bath as she had not felt safe bathing in the presence of a particular care worker:

“I wouldn’t say it to them necessarily but I would know straight away that I don’t feel safe, I wouldn’t feel safe. Yeh I would then say that I won’t have a bath to them and that’s to my detriment. That day I would probably have a few more hurts in my body than I would like although I do have pain patches on me.”

The intimacy required by many tasks also elicited feelings of embarrassment, experienced both by the care recipient, and perceived in the care worker:

“She was very embarrassed right at the very beginning with somebody washing her down. She was very embarrassed but she’s fine with them now, she’s got used to them coming in.”

“When they take her into the bathroom to wash her and that, they seem a little reluctant to do it. I don’t whether they are embarrassed or what but I don’t feel that she gets a good a clean in the morning which I think is the essential time for it all, as she should do but that’s the rarity.”

The Organisation of home care choice: the next step – influence on type and level of care

“Nobody rung us to warn us that it was happening, so this girl turns up and we didn’t know who she was.”

This section will focus on one of the most dominant themes, agency and control over care services. The main emphasis will relate to issues concerning choice with specific reference to type and level of care, issues of choice relating to logistical implications

such as timings and consistency/regularity of carers will be discussed in subsequent sections as they were very significant themes and warrant their own focus.

Although it is evident from the findings that the majority of participants, for the most part, found the advent of a home care service to be ultimately positive in relation to their autonomy and well-being, it is apparent that it is not unproblematic, especially in the transition period. As discussed previously the act of letting strangers regularly into your home changes the relationship between a person and their home. The transition of private space to a semi-private space can be challenging both in the long and short term. Care at home can create a living environment that may be perceived as an unnatural infringement on one's privacy, dignity, and personal freedom. As a consequence, the transition and the consequent loss of independence may also take its toll on mental well-being:

“She never feels safe. We’ve had to take all the locks off of the doors because she was locking herself in and the carers couldn’t get in, I couldn’t get in. So we’ve had to take those off the doors and take her keys away as well because she was locking the door so we took the keys away but they are still here somewhere.”

It is evident that the advent of home care is complex and needs effective planning and developments. Involvement in the process of developing care packages can positively impact on the success of the programme and provide the recipients with a sense of agency and control. The “10 Dignity Do’s” published by the Dignity in Care campaign promote, among other points, the importance of enabling care recipients to “maintain the maximum possible level of independence, choice and control”. Participants in this research who are in receipt of home care had very mixed experiences about the initial organisation of their current care. Only 11 respondents felt they had had a say over the help they received, and some had experienced unwelcome service disruptions transitioning from re-ablement to longer-term care. Carers involved in the process were especially critical of the mechanisms involved.

It is evident from the findings that the extent to which individuals were involved in the planning of their home care varied widely. There was a complete range of user involvement reported, with some respondents feeling they had full input:

“They basically put a plan in and you sort of pick and choose what is more beneficial to you. So yeah you have full say on what you require sort of thing,” and others saying they had no input on the process of choosing care provisions that matched their needs: *“we didn’t have a say really, they just told us what we were having, suppose I just thought they maybe knew best.”*

The need to involve recipients in the development and on-going provision of care was a recurring theme within the findings, seemingly in contrast with the “person centred planning” objective prescribed in “Putting People First”, a paper published by the Department of Health in 2007. Many recipients felt that their input was limited to financial matters, rather than based on need and they expressed dis-satisfaction with this approach:

“[...] social services in hospital were absolutely atrocious [...] they were totally incompetent, you could never contact them. [...] I think the other thing that I found was all the questions were driven financially and I totally understand the way things are at the moment with cut backs, but everything was “do you own your own house”, “how much savings have you got” and those are the initial questions it was not about what are mum’s requirements.”

Another interviewee user was even more incredulous about how he had been treated in the early organisation of his care when he was paying for the entire serviced:

“They contacted Bexley Brokerage which I thought was a laugh. They are telling us who we are going to have and we are paying for it.”

Even when participants felt that they had been listened to in relation to the choice of care providers this process was not unproblematic. When the care plan was not satisfactory and recipients wanted to make changes a number of respondents reported waiting a long time before their input was acknowledged or acted on. In addition many talked about feel anxious that any pressure they may exert could result in a complete change in providers and a resultant loss of relationship with their current carers. One 88 year old respondent reported having problems but not requesting a change of provider:

“I just chose [company] because I liked the name. Anyway since then I’ve had them and I haven’t changed them or anything even though I don’t often agree with them.”

These difficulties identified were evident whether the change was instigated by the care recipients themselves, owing to dissatisfaction with the organisations providing care, or whether the change was imposed upon them. One respondent reported difficulties arising from changes made to care-providers seemingly enforced by the council without input from the care recipient:

“I was told that it was policy from Bexley council that we could not stick with the same company that it had to be changed. That’s why I had to move from [company A] to [company B] which was a bit – once we got used to one set of carers coming in, we had to start again with another set.”

The difficulties involved in changing carers was echoed by the following interviewee, who spoke of her 86 year old mother’s concerns about the family’s wish to change care provider, and then the lack of communication throughout the changeover process:

“We did have social services were coming round and different things and we had been saying to them for at least 6 months that we wanted to change. When I wanted mum to change [...] she was always a bit worried about doing it because of the cross over and upsetting some of the girls that she did like. Once they all left, she said ok we’ll change. I think social services recommended it but nobody rung us to warn us that it was happening, so this girl turns up and we didn’t know who she was.”

According to some participants it was possible, in their situation, and fairly easy to have an input in the decision relating to the care provider, although this may not have drastically altered the care plan it did give them some agency in the decisions relating to their care:

“Initially the council just sent an agency yes. That agency dealt with me for some months and then, I wasn’t really happy with some issue with them and I changed to the one I have now.”

“Well they told me what time they thought I could manage with and that’s all they stick with. I think, they are very good; they will listen if I phone up. I don’t complain any more than I can help because I know they do their best.”

It is evident from the findings that even if recipients are happy with their care provider (or the changed provider) the degree of control over which services are accessed to facilitate care recipients’ chosen lifestyle was problematic and featured as a key factor contributing to quality of life for the disabled adults featured in the research of Vernon and Querishi (2000). Overall, care recipients in this study felt they had only limited influence over the type and level of service offered by a particular home care provider. Some care recipients referred to perceived resource constraints as the reason for this, as well as restrictions relating to their own financial situations. Some had requested a greater level of care, while some care recipients reported an attitude of settling for care that did not meet their needs, without asking for more, because they believed that the budget would not be available.

Most respondents had an awareness of the economic climate and the effect of this on the availability of social care, and many reported having requests for further support being turned down owing to lack of funding:

“[...] I said that I didn’t feel that 15 minutes was sufficient time and I was told that was all that was available and that could be provided.”

One 93 year old with arthritis spoke of ongoing assessments, reflecting on the perceived pressure on care providers to reduce costs by reducing service provision:

“I feel sure if I needed any more help which I might as I get older that I would apply and they would send someone here to assess me you see. They do send someone about once a year to assess your needs and to see if they can cut corners and things, perhaps I shouldn’t say that. In truth, it’s the truth isn’t it because they have a budget to keep to and there’s so many of us nowadays to look after, not only people like me but people who are unfortunate enough to have dementia and things like that.”

Personal finances appeared to be an obstacle to receiving adequate care, as some interviewees reported a reluctance to increase their care provision to better meet their needs in case it was no longer affordable for them, as one 85 year old living with Parkinson's describes below:

"[...] they'll come in to me round about 8 o'clock although we did arrange for them to come first of all earlier."

"[Interviewer:] Have you been able to talk to the council at all about how you feel and that maybe you would prefer to have more, that you would like more care?"

Well I have to pay for it now so I'm a bit worried about increasing it too much."

The interviews repeatedly highlighted the wish for care tailored to the individual's preferences. For many respondents the feeling of being totally out of control of their life was a common theme. The lack of choice in how they were cared for was very distressing. The quote below draws attention to an issue relating to a care recipient's dignity and choice in the way her toileting is managed, preferring to receive help to get to the toilet rather than relying on pads:

"Well [care recipient] has always been a private person as far as her body self is and a very clean person. [...] she will not wet herself in a pad, she wears an incontinent pad all the time but in hospital they used to say to her 'oh do it in the pad'. She would ask to go the toilet but they would tell her not to worry about it and do it in the pad and they'd change it later. She would not do that, she would try to get out of bed and go to the toilet by herself but of course she would get out and fall over. In that respect the girls are, particularly the one in the morning who washes her, she will get [care recipient] to do it herself if she can. Depending on how she is at the time." (Family member)

This approach was unfortunately reflected in a case at the European Court of Human Rights in the case of Elaine McDonald, where the court held that her local council did not breach her private life rights following a reassessment of her needs which determined she should be provided with incontinence pads, rather than continue to receive funds for assistance for her to use a commode through the night. The court did find an initial breach of her private life rights in the period before a proper reassessment of her needs had been carried out. This breach was because her

original care plan had stated she required assistance to use a commode, but the decision to withdraw this support was made without an appropriate reconsideration of her needs. The court stated that once the reassessment had been carried out properly the council had a wide discretion as to how it allocated scarce funding, even though the proposed care plan did not match the wishes of the claimant.

The interviews undertaken in this research highlighted the evident concern relating to the degree and depth of care given, anything above the bare minimum in relation to physical needs was a struggle to achieve. This was particularly true in the fact that care did not extend to fresh home-cooked meals, and most respondents relied on cold/ microwaved meals through a separate service. One 85 year old who taught cookery before her retirement became upset while relating how difficult it was for her to prepare food for herself, so lunchtime meals were prepared for her in the morning. She said that, if care was available, she would like to have a lunchtime visit so that she could have fresh, hot food, as well as support staff to accompany her to appointments:

“[Interviewer:] Well let’s just think, that, say if we didn’t have to worry about money, what would make like for you better?”

“To see someone lunch time. [...] Have a fresh cup of tea and a warm lunch. I try and do it myself sometimes but sometimes I can hardly stand up (participant cries), I have to come in here and sit down and my heart’s thumping and I feel really bad. I do try sometimes; I did cook a casserole one day last which I was pleased about. In a slow crock pot it was lovely it was nice to get some fresh food.”

“I need care all the time. I hate being like this because I’ve always been a very active woman and I worked ‘til I was 60. I used to keep the house and the garden clean and things like that and then suddenly when something strikes you down and you can’t do it, it’s suddenly hard to bear. In the beginning it’s very frustrating and very tearful about the fact that you’ve got to have someone to do something for you but I’m lucky that I do get someone to care for me”

Many respondents talked in terms of the 'pain' of having roles taken over in the home without their involvement that took away their independence (Vernon and Qureshi, 2000), this is exemplified by the care recipient quoted below:

"because I have to wear pads and that and they do need 4 hands to put them on really. When the carer, it's part of their job they hold it and I'll reach down and I can get them one at a time and bring them round the front and have to pull them tight otherwise they fall off... well I was reaching round and this girl smacked my hand as I was..... I said "I'm only trying to help" she said "that's what I'm here to do isn't it", so I didn't say anymore but I did phone up the office and she was removed from my itinerary".

Ryburn et al (2009) emphasise the importance of home care that supports the individual to maintain function, rather than encouraging clients to "become entrenched in a 'sick role'" (p. 226). A number of respondents spoke of their wish for support to retain independence, with some praising care workers for encouraging them to do things for themselves:

"They do try to help me to do as much as I can which is good really, keep myself going as much as I can."

"Yeah, they are good because they don't push themselves on you they know when to sort of step back and let you muddle through. They still sort of, I presume their idea is to, if you can do it they will just stand and watch and if you have trouble then they will help sort of thing so..... Yeah because as I just said I'm quite independent so I will bugger about trying to do things myself and when they can see I'm having trouble then they will offer a bit of help which is probably better especially for different types of people. Obviously some people want more help than others don't they, so Yeah they are good at that."

Many respondents spoke of their feelings of powerlessness and that the care they received was creating dependence, rather than facilitating independence:

"I feel useless myself. I can't contribute anything these days. I feel I can do anything."

Krause (1987) suggests that when stressful events occur in the lives of older people, as are more frequent with the deteriorating health associated with aging, individuals

tend to allow themselves to identify with the negative stereotypes of dependency and weakness. Krause asserts that this internalization of negative stigmas dramatically lowers self-esteem and can have negative effects on an individual's resiliency to both physical illness and mental well-being. The type of care system needed is therefore one that helps those in need of care not to fall into these 'roles' and to maintain self-awareness and independence where possible.

The time allocated for carer visits inevitably has an impact on the time of care given and the ability of carers to involve the recipients in their own care. Two respondents reported that their home care felt rushed, creating a pressure that Deci and Ryan (2008) suggest depletes motivation for autonomy. One 95 year old widow explained how she felt that care workers were rushing her to complete tasks:

"I had a carer yesterday, she was very nice but all the time she was rushing me and the time she finished I was exhausted, absolutely out of it for the rest of the day. It's very hard, I'm not being critical, I'm not being unkind because I know within their time they are doing the best they can."

Another 85 year old recipient of care told us she too felt obliged to allow care workers to do things for her because of time pressures:

"I'd rather, really make errors if I have to when I'm feeding and just get on better by continually doing it myself but slowing up. Sometimes it seems necessary to let them take over and speed it up somewhat."

Logistical implications - timings and lateness

"So a couple of times they've come and I've said it's too early, I'm not a toddler but you've got to be with them, work with them because they've got their list to do."

One issue was raised consistently by care recipients: lack of punctuality and reliability in terms of the timings of care visits. Many felt that although they had been given choice over timings, these were not necessarily adhered to. Related to this was a lack

of communication regarding the time when a carer could be expected, or whether they could be expected to arrive at all. Issues around lateness were mentioned in 19 out of 26 interviews. Some interviewees also reported dissatisfaction with the scheduled timing of visits, this lack of choice meant that care recipients were not able to get up and dressed or ready for bed at the times they wanted. Respondents said they had been told that this was due to the popularity of certain times, which meant the providers could not meet everyone's request, resulting in care tasks being carried out at what Twigg and colleagues refer to as "‘meaningless’ times that conflict with normal social ordering" (2011: 177). The effect of this was to affect the potential for attaining one's own goals or standards (Vernon and Qureshi, 2000), thus impacting on self-esteem. Although there were some positive examples of carer flexibility in terms of timings it was evident from the findings that lateness resulted in anxiety, uncertainty, disrupted routines and, in the worst case, accidents in the home with potentially serious consequences. This is a significant issue especially as guidance produced by the Equality and Human Rights Commission (Your Home Care and Human Rights, 2012) emphasises the right of care recipients to choose to receive care visits at appropriate times, to allow individuals to live life as they wish.

The feeling of not being in control of the timings of scheduled care visits was mentioned frequently, so to was the frustration at planned visits not happening when they were supposed to. One family member spoke about the inconvenience of having to plan their day around care visits, whilst at the same time not feeling able to depend on carers coming:

“There’s nothing I can depend on and indeed, my life is on hold because you were coming this afternoon I dashed round [...] this morning to the pharmacy, I had something like a short hour to get a prescription picked up. “

One 77 year old living in Welling, whilst initially expressing satisfaction for the service, later spoke of appointment times getting later over time and so affecting her personal schedule, social contacts and sense of dignity:

“Oh yes, I’m very satisfied with [the company]. The only question I had about it is when I first came out I was priority so I got an early appointment for breakfast and then since November it’s been getting later and later and sometimes it’s

half past nine, quarter to ten, that doesn't suit me because I sometime have people coming in to see me at ten o'clock and I'm not ready."

Many interviewees recalled situations where the timing of their care had reduced their personal control of planning their day, potentially breaching their right to a private life guided by their choices:

"I do object when somebody comes here at half past five to get you undressed ready for bed especially in the summer. Someone calls anytime between 8 and 9 o'clock which is quite nice for me."

Weekends were reported to be particularly difficult for services users, who experienced an increased frequency of carer lateness, and less consistency in the carers coming to their home. Some interviewees said they had come to expect care arrangements on weekends to be disrupted on weekends owing to regular staff sickness:

"[...] weekends are murder, you know on the weekends that they are going to be late whoever, because they would have had five or six people go off sick every weekend."

Others spoke of the frustrations of not knowing who to expect to be providing their care over the weekend, and what time they would arrive:

"Morning and evening they are the same carers. Weekends, it could be anybody and it can be anytime which is very very annoying at times."

One person interviewed described having trouble predicting when caring staff were due to arrive, as they did not have fixed times and the visits were not consistent:

"[...] we do not have allocated times. Sometimes they will come and in and I've said to them 'Well you're late compared to other times' and you realise, we are slowly realising that they get here when they get here and they sometimes get extra people in their round so they're even later. We've never been given a specific time actually."

The son of a 101 year old care recipient offered to produce time-sheet evidence of the inconsistencies in the timing of the care provided to his mother:

“I mean I can show you some of these weekly sheets and you get all the different times.”

One family member described the potentially serious impact of booked timings not being adhered to, when a lack of punctuality for two consecutive care visits resulted in her late mother being left alone for 10 hours, and another incident when care staff did not arrive at all:

“Sometimes they were 2 hours late, sometimes they were 2 hours early. One day, a couple of occasions no body turned up at all to put her to bed and she had to spend the night in the chair all night. Other times she was just left for 10 hours a day because of the first one being early and then the second visit being late and the one in the middle being missed so it wasn’t sufficient no.”

One 88 year old interviewee did speak positively of their arrangements, but still noted that care delivered on time could not be guaranteed:

“[...] they said that what time would you like and I said well about 6.30-7.30, that would suit me fine. I must admit nearly, well most of the time they do.”

The timing of scheduled care was not the only issue highlighted in this research, lateness of caring staff was a serious theme not only affecting care recipients, but also impacting on family care-givers, who relied on paid carers to relieve them so that they could be elsewhere:

“The only problems that we’ve got are weekends when they know I work, they are turning up late, especially on a Saturday, Sunday night. I’ve been late for work twice in 20 years and both of them are down to this caring firm after the last 2 weeks.” (Family member)

Not all respondents emphasised the issue of lateness of caring staff, those that did highlight some of the realities of relying on others spoke of the negative impact it could have on themselves and their family. This impact ranged from relatively minor inconvenience, to incidents threatening the dignity and safety of care recipients. Some respondents also spoke of social engagements having to be cancelled because carers arrived too late to help them get ready in time:

"I did have cause to complain because when Wednesday is the only day that I normally go out in the morning and it's sods law that Wednesdays the day that they are going to let me down. Well not completely, but they come too late, that came at quarter to eleven was It (refers question to his wife), fairly recently. I was so angry, I was angry about that because, yes I can get myself out of bed and I can get down here, but I can't put me shoes on so I can't go out."

Other care recipients talked about having to wait for food or drink, with meals being provided later than they would choose, and large gaps in between sustenance provision:

"[A different carer] on Sunday evening and it has been a problem. Well sometimes she doesn't come till 8 o'clock at night and I'm starving by then, I get past it and I don't really want a meal"

"The other day I didn't get the morning call until 11.30 and of course during that time, I can't get out to make a cup of tea or anything so... and I'd drunk all my water that they left me the night before."

A 77 year old amputee spoke of the stress and frustration of not knowing when or if care workers were going to arrive, and the affect this had on her ability to go to the toilet, eat when hungry, and see friends as arranged:

"I've had to cancel [social arrangements], the toilet's a problem and breakfast is a problem, I'm hungry. [...] I sort of had to work it out for myself what had happened. Someone had been given my slot or as I spoke to a couple of the carers, this lady in front of me, she'd got worse and she needed longer time which is very sad but I don't want to be waiting here until half past ten for my breakfast and that. "

The son of one 101 year old respondent spoke of recording a large accumulation of periods of missed care, resulting from both late arrivals and shortened visits:

"The morning visit usually is half an hour times 2 women. But if they can get in here – sometimes the morning visit is very late and they are not leaving until about 12 noon and I say 'it's not worth coming back is it at lunch time' and so they don't and so we cancel that, so that's an hour off. At lunch time or in the

evening they might be here for 4 or 5 minutes, 8 minutes, I have kept a complete record of this.”

Two respondents observed that visits were sometimes more than an hour late, but that they were not given notice to allow them to plan for this. Both said that they had requested that care companies contact them in such situations, to give them the choice to cancel, or the chance to make alternative arrangements:

“[Company] could be better if the person can’t come within an hour of the time they’ve got on their sheet they should ring up and say ‘I’m sorry Mr H I can’t get there ‘til so and so, do you want me to cancel’ and I’d say yes and get myself ready. So it’s just a bit of communication but nothing improves in that manner.”
“[...] when we had the trouble, wife phoned them up and said “look if you can’t come within the hour that they should be there, please can you let us know” but they don’t do that.”

One family member spoke of a series of unfortunate errors with their mother’s care provision starting with the late arrival of care staff. On this occasion it meant her 90 year old mother had not been helped to use the toilet in time. The care recipient’s daughter described having to provide care herself when the care provider was unable to respond to her mother’s emergency alarm call, after a bad fall which she said caused haemorrhaging to the brain:

“[...] the carer was an hour late for her teatime visit and came at 5pm. When the carer come, mum had wet herself in the chair so the carer just put a tea towel on the chair and that’s when she was put to bed at 8pm and that time they did turn up on time but mum had a fall after being put to bed because she was trying to switch the light off in the bedroom which the carer had accidentally left on. No one could attend because, she pressed the alarm, the company were unable to send somebody round because they didn’t have anybody available so I drove a hundred miles round trip and spent the night on the sofa just to try and deal with the situation. So that’s an example. [...] It’s difficult to say but she may have even been around here now because the fall that she had to switch the light off where she hit her head did give her bleeding on the brain.”
(Family member)

Many participants talked about the negative impact carer lateness had on their ability to partake in their chosen religious worship. It is evident from the findings that many found this particularly distressing. Although “Freedom to manifest one’s religion or beliefs” is protected by Article 9, Section 2 of the Human Rights Act 1998, for some people receiving care, this freedom is restricted by not being able to depend upon timely help to make worship accessible to them. A gentleman who had been receiving care for 7 years spoke of the impact of carer lateness on his family members, and also on his ability to engage in worship:

“I get upset, I look forward to going to church and seeing people and being part of it again, I would go every week but with the carers changing times it’s not possible”

“The carer comes of a morning Monday to Saturday inclusive and she’s very good. When she has to have holidays somebody else comes and if they don’t come on time I get concerned because wife likes to go in the bath by 9 o’clock and it upsets the household. On a weekend, we’ve had relatives staying with us last weekend and nobody came to help me get ready to go to church so I had to ring up and cancel them.”

“I have to cancel all the time, it upsets me, I never missed a day before, they come and visit [priest] sometimes but it’s not the same, I cry sometimes, I just cry.”

The inability to continue with religious worship was an obvious source of sadness and regret. Paul Wink and Michele Dillons’ (2003) study on elders and social support highlighted that deep religious beliefs increase a sense of well-being and personal growth. The study also highlighted that the development of positive social relationships through church community involvement may in fact be the actual source of a sense of well-being (Wink and Dillon, 2003). As the population of church going elders gradually lose other sources of social support the religious community is able to provide an alternative source of social interaction and relationship building.

As mentioned there were positive reports of carers being flexible, where possible with their timings for the benefit of the care recipient, with interviewees expressing appreciation for carers who made arrangements to “fit in” changed visit times:

“[...] if I have a hospital appointment and you always have to be ready two and a half hours before the actual place. She [carer] will actually come in early for me, extra early. She’s very very good like that and she can fit me in.”

The above quote exemplifies the gratitude some care recipients expressed for when they felt care arrangements were personalised to meet their needs, both ongoing and changing. Spontaneity and flexibility are restricted when one has to plan one’s life around care routines, limiting the ability to fully engage in social life (Gibson, 2012). Flexibility is also important for the establishment and maintenance of positive care worker-client relationships (Eustid et al 1993).

Tolerance and empathy for workers and providers:

Some respondents appeared tolerant about carer lateness, sympathising with possible reasons (care emergencies, staff turnover, staff sickness, tight schedules, poorly paid staff, staff childcare issues, transport issues), while others had changed their care agency because of this. Others understood that staff lateness sometimes arose from scheduling problems, meaning that staff had long journeys to make between appointments. The 80 year old retired nurse cited below put the blame for this with the agency:

“Now this young lady today she, just for an instance, she lives in Greenhithe, she had been to Crockenhill before she came here and after she had done me she had got to go back to Crockenhill ah... doing lunches and of course she was very late, I mean I rang this morning and said ‘well is anyone coming this morning to help me’. [...] I said to the office here, I said, ‘if you, if you had to pay petrol money, I said you would be getting your finger out and sorting out all these things’”

Another participant noted the difficulty some care workers have with getting to appointments when they rely on public transport, this eventually precipitating him to change to a provider whose staff travelled by car:

“We did have another agency, but there’s been a couple of agencies erm and it was difficult cos the last agency that I used erm that hadn’t got cars so they used public transport and it was really difficult to, you know, they’d be coming at all hour really and er I think the level of care was not good at all. [...] This [care company] is very good, they have cars so they, they can more or less say what time they are gonna get here and that’s very reassuring.”

The husband of a lady in Bexleyheath with Parkinson’s noted that weekend schedules were particularly prone to delays, but again assigned no fault to the carers themselves:

“[...] the weekend is bad, when I say bad it’s because their times are mixed up and you might not get them until 8 o’clock, not their fault that’s their list and they have to follow what they’re doing.”

A retired teacher said she understood that the carers’ schedules did not allow extra changeover time to safeguard against delays for the next client:

“If they get held up then you’ve got to understand that the traffic’s bad or things have happened to them.”

Empathy was not just limited to care workers; many respondents expressed sympathy for the care provider companies. The quote below, from a respondent who received care at home following a heart attack, demonstrates the empathy extended by some towards care companies, suggesting that some individual members of staff do not help them to deliver timely care:

“Unfortunately for [the care company] some of the girls they don’t always phone in and tell them they are going sick, they just don’t turn up which is very bad really. But then that’s not the managements fault either, that’s down to the person that they are actually employing. No doubt they get – well I know that they get disciplined over it, that’s nothing to do with me. As I say it’s just a sign of the times really.”

Another 55 year old with Multiple Sclerosis respondent blamed staff turnover for problems in care provision:

“You can’t really fault that because they’ve all got to have their staff turnover so that’s the only quibble I’ve really got which isn’t one really is it, it’s the way of

the world, people need their jobs [...] that doesn't happen a lot so yeh no worries."

The daughter of another recipient of home care spoke of technology failures contributing to inconsistencies in care, particularly in relation to communicating with staff:

"Yes and they put you through to an emergency but they've all got these mobile phones and apparently the signals are really bad and the phones don't work. They are supposed to swipe in on a little sticker downstairs but the phones never work, so they can't ever get hold of the carers."

She also felt that emergencies with other clients were used as an excuse when carers were late for visits to her mother, who has difficulty getting around her home:

"One night they didn't get here until twenty to ten. 'Oh there's been an emergency' but that's bog standard answer that you get for any care when you ring them up they stand fast" (Family member)

One respondent who receives help at home to dress, apply creams and have breakfast, felt a need to be "fair" to carers and their employers, and understand that many people would demand care at the same time:

"I'm so happy with the actual care we are getting that, yeh it would be nice but I can understand why they can't always provide regular carers. And as I say as an individual you might get a bit uptight about it but then again you've got to be fair, a lot of people probably want the same sort of care, are on at the office just the same."

Interestingly, the daughter of a 93 year old with Dementia and sensory impairments noted inconsistencies in the time of their carer's visits, but did not feel that this mattered to them:

"[...] sometimes she can come in at 8 am in the morning, sometimes she's here at 6.30am. It can differ but that doesn't really matter."

Lack of consistency - carer regularity

“She said to me that she couldn’t build up a relationship with carers because she was seeing different people all the time and she didn’t know who was coming in and out of the house.”

Another issue that was raised frequently was related to staff members who were not regular. There was a strong preference among interviewees for continuity of care worker. Irregular staff issues were usually mentioned in relation to weekends or days when regular carers had their day off. The implications of irregular workers included lateness or staff not knowing what to do once they arrived. On some occasions, this would prevent care recipients from undertaking their own activities, such as going to church or going out. It was also mentioned by some care recipients that the lack of knowledge and training of temporary staff meant that they did not always feel confident in their abilities or well treated by them. Some interviewees spoke of the difficulty of building trust and relationships with care workers, when the staff members visiting them were not consistent. They also reported frustration in having to repeatedly explain to different people their care needs and personal preferences.

One 86 year old respondent said she found it confusing to have difference people visiting her. The response from the home care service was however considerate to her concerns and she was able to have a consistent carer for most of the time which had improved her quality of life:

“I see so many people and I can remember everybody’s name. I’m alright with some, some I get a muddled up a bit. I get, because I said I like consistency, now I have 2 young women who come to me Monday to Friday, they come every morning and I’m very pleased with them and got very friendly with them now. They are very good, very caring and they’re observant of different things.”

A number of interviewees spoke of the difficulties arising when care workers were unwell, but recognised the challenge this also caused for care services:

“[...] when the carer that you’re down for and was going to have, she might phone up in the morning and say ‘I won’t be in today or tomorrow and the doctors given me a certificate so I shall probably be off for three days’. Well then for the girls in the office it’s a difficult job that they’ve got, they’ve got to

replace all the carers of the different people. Sometimes they can be, I've really only had one carer that I got really upset about [...]"

"It's a bit awkward really. I do have what they would call a regular carer but then she's never available on a Wednesday, she's not available weekends so I have another carer for the weekend, usually regular but I think they are going through a bad patch because at the moment, anybody seems to be coming. They are being let down by staff going off sick, I think they are short of staff in some respects."

Care worker sickness affected many of the care recipients interviewed. One family member explained how long-term sickness affected her late mother's care, and the difficulty this caused for her in developing positive relationships with carers:

"There were 4 or 5 different carers turning up at all different times. When I asked [...] the care company about that they said that was because her normal carer that was allocated was long term sick, in fact she was off for about 2 months in all so my mum was just being slotted in by trying to fit her in with other rotas so that was why she didn't see the same person. [...] she said to me that she couldn't build up a relationship with carers because she was seeing different people all the time and she didn't know who was coming in and out of the house."

One 85 year old with Parkinson's empathised with the care workers substituting for colleagues unable to make scheduled visits:

"They [company] are very good but when they have to fill in with somebody that doesn't know the area or doesn't know me its awkward for them, new person coming in so I can understand it's not very pleasant for them. I dread it."

One respondent, who has help at home with washing, dressing and preparing meals, noted that inconsistencies in care workers owing to ill health worsened over winter months:

"[...] in the winter when a lot of them get colds and that and stay at home, don't work obviously and the.... This particular weekend I had six different carers on that Saturday and Sunday and every other day of the week I had either two of three carers. I've never had a complete week with just one carer."

There were also differences reported between different care providers with regards to helping services users know who to expect.

“With [care provider A] we do actually get informed a week in advance who the carers are, when they’re coming, have nothing like that from [care provider B]”.

Care recipients and family members also spoke of the difficulty irregular carer workers had in relation to their expectations of care with their treatment being ‘pot luck’ as to whether it was a known carer who would treat them with dignity and respect or an ‘unknown’:

“The ones that were coming in and out, because they were varied and so different, they only used to come in... I used to see a different face every time so I couldn’t really say. The carer originally that was allocated to my mum, I would say yes they did [treat care recipient with dignity and respect], but that only lasted a short period of time and because there was always a different person coming in every time I couldn’t really answer that fairly.”

Frustration with multiple carers was a common theme. One 86 year old woman receiving two visits per day spoke of having at least 30 different carers and finding this very difficult, feeling that replacement staff did not understand her needs or were not adequately trained:

“This is a bug bear, absolute, been a bit of a nightmare over time. I could stop counting after I had 30 different carers and I’ve had all of that and more since extra. I just can’t, I’ve lost count altogether the amount of carers that have come. [...] I’m still at this stage, the only one I can say I’ve got as a regular carer now is my morning carer. But that’s only been in the last year that I can actually think she’s my regular carer. Otherwise they just turn up, you know and that’s not satisfactory, they just turn up anybody. [...] The fact that if your carer happens to be off sick, they’ve got to cover and you get some stranger who don’t know your needs, don’t know how to handle you and I know it’s hard, very very difficult to cope with that sort of job, the care agencies but sometimes you feel that they’ve not had training themselves.”

Frustration resulting from having to repeatedly instruct different carers on care requirements was repeated by a 55 year old ex-plasterer, who said this was compounded by language barriers:

"[...] my regular carers are great and I can't fault them at all but every now and then they obviously have quite a high turnover of staff and they might send someone who doesn't speak very good English, who you have to tell them what you require. When you have that over... when you have a new one every 2 or 3 days, it gets a little bit monotonous especially if they don't understand you as well because I sound like a barrow boy at the best of times so if someone's not English then I'm trying to explain to them what I need, it can be a bit monotonous."

These frustrations were again echoed by another recipient of care, who found that unfamiliar care workers had difficulty in using equipment and finding what they needed in her home:

"I've had carers that don't really know what to do because they don't know my kitchen, they don't know the hoist, but I know the hoist so I can tell them what to do, how to hook it up. They go out there and there's all those cupboard in there, don't know where anything is but they soon get to learn and you can't blame them for that really and husbands about here if he's not asleep."

For one family member, lack of continuity of care was a large factor in the decision to give up his work, so that he could increase his availability to care for his mother himself:

"It really is a battle just trying and all we want is a decent carer, continuity and reliability. The carers coming at 11 o'clock in the morning and I'm fighting this and doing a full time job so I'm actually giving up work so I'm going to start caring. I'll carry on doing the weekends because I accept getting carers at the weekend is nigh on impossible." (Family member)

For some care recipients, continuity of care was an issue of safety, particular for those for whom sensory impairments made it harder to identify people, or for those who had developed systems within the home to keep them safe and enable them to find certain items:

“[...] obviously continuity of care for someone who is visually impaired is really quite crucial isn’t it. When you don’t know who you are letting in through that door and that voice changes on a regular basis. [...] I do notice mum gets quite unnerved and unsettled when we have different carers and we’ve just had 4 in the last 2 day.”

“[Family member]: That’s the trouble because they don’t come regularly, you can’t get in a routine. I think getting in a routine is important.”

“[Care recipient]: It is. Yes I have to ask them otherwise which day it is and so on because there aren’t clocks big enough or all saying the same thing. That’s the thing, but I think some of the new people too may be if they are in a hurry, they find it very difficult to point out where things are and where they should stay. I have little bits of sticky cardboard that I put glasses on and then it’s fairly safe to get hold of and you come to recognise the shape of the tops and that shape of the glass and you get used to a certain place but if they’re put anywhere else, very mystified.”

“[Family member]: So her carers that don’t take that into account and they will leave a plate and you will knock on the floor and the plate shattered on the floor, or there will be drinks knocked all over the floor.”

There was a perception that high staff turnover was another factor affecting continuity of care. One respondent, who had been receiving care at home for 4 years, described the frustration expressed to them by care workers themselves, who reportedly felt that they were not able to provide the quality of care the role deserved, because of frequent changes in assignments:

“I’ve seen so many that’s come and that they have got it in them to be good carers but because of like I find you keep getting different one, I find they get pulled down by being sent from pillar to post from one to another. They’re not able to get to know anybody properly before they are given a round. It’s not fair all round so and I’ve seen a lot of them that have been really good carers had they not felt that way and felt they couldn’t stand it and had to leave.”

Although the majority of respondents had issues with the inconsistency of carers and often multiple carers not everyone felt that it was a significant enough issue in terms of their care. One gentleman, whose home care was arranged by the hospital after a heart attack, did not report difficulties resulting from lack of continuity of care:

“Even with the odd ones that come in, I’ve got to be fair, they’re all pleasant, they all do their tasks and I’ve got no problems with that at all.”

The caring relationship - Positive carer interactions

“Some of them, they’ll come in and they’ll say “oh you’re upset [name] what’s upset you, come on now”, so they come over and get hold of your hand and ask me to tell them (laughs). It’s quite comforting, absolutely.”

The previous section outlined some of the more negative elements of home care when the relationship or process can go wrong. The dynamics of human relationships are complex at the best of times, when relationships are imposed, in the sense that they are developed out of necessity rather than choice there is an evident need to ensure that they are managed and supported in the best way possible so as to allow for human dignity, safety and respect.

Lindahl, Lidén and Lindblad (2011) emphasise the importance of services users, along with their family members, developing “friendships” with home care staff, for the professional relationship to be successful. Our interviewees discussed the difficulties in allowing strangers into the home to begin with, and then the importance of continuity of care, which is discussed later in this paper.

An unsurprising finding of this research was that recipients of care valued carers who were regular, experienced, empathetic, attuned to their’ emotional as well as physical needs, well trained and dedicated to their work. Most care recipients felt treated with respect and dignity and many praised their carers for improving their quality of life and enabling them to stay in their homes. Although there was a sense in some responses that domiciliary care could never quite replace round-the-clock familial care, most respondents were grateful for the quality of interactions they received in the absence of family care. The perceived competence of carers was discussed by participants

with many expressing gratitude for carers that demonstrated professionalism and knowledge. The quote below from a lady, who shares her mother's care with paid staff and a neighbour, highlights the range in perceived competence of care workers, with one worker being praised for checking the work of others:

"[Carer] reads all what the other carers say and if she notices they're not doing she will put a note in the book. ... She's right on top of things, she's very very good. I think she's done that job for years and enjoys it I think as well."

The value placed on particular carers went beyond perceived competence with priority given to carers that treated them with compassion, empathy, and were generally friendly and interested. A 77 year old retired teacher, who lives with her husband and has help with personal care and meals, spoke of how her relationship with her carers was so much more than the tasks they were assigned to carry out. A personal relationship was developing and she gained much pleasure from hearing about the lives of her carers:

"[...] they're friendly, they're sociable, they're like a breath of fresh air when they come in because.... Ooh they're all getting married at the moment and getting engaged and having babies. It's lovely, they're lovely girls."

The husband of a 73 year old with Dementia talked about how different care workers provided different things and although the practical elements of care were extremely important his level of satisfaction correlated most closely with the quality of the relationship engendered by carers. He placed a high value on hearing laughter shared between his wife and her care worker:

"It was difficult at the start to let people in, but you get used to it, some are better than others. Well particularly the one in the morning, she's very very good because I hear them in the bathroom chatting away and laughing and joking. The one in the evening, it always seems to go that she's in and out. She can't, she can't wait to get away." (Family member)

This was reinforced by the daughter of another recipient of care:

"There's always laughter going on, I'm down stairs and I can hear them laughing up here so that's what you like to hear isn't it." (Family member)

The disposition and attitude of carers is evidently an important aspect of the home care relationships. A study by Nancy Westburg (2003) recognised that hope and laughter serve as useful resources as elderly people's support systems shrink. Westburg's(2003) research demonstrated that hope and laughter both serve as internal coping mechanisms and that creating environments that foster these attributes in individuals may produce positive results in decreasing levels of depression. Most respondents reported that the attitude of their care workers made a big difference to their quality of life, one 88 year old respondent commented that positive interactions with care workers made her feel life was worth living:

"I keep on saying it, it's the older carers that you get and that's very nice and very good and I really must, I can't say enough on their behalf because they are so so kind they really are kind. [...] Well as I say, the older ones, the older ladies and when I say older ones I mean people over 30 and that, they're always good and they make you feel it's worth living and that sort of thing. You can have little talks with them and that, it's quite encouraging."

Another care recipient who receives care at home after an operation for cancer caused complications, spoke of how important it was for her that care workers showed not only skill in performing their duties, but that they also care about her and are able to demonstrate this:

"Well there's skills in their own personalities and the interaction between us, that quality, you know the caring part of caring is very important as important as what they are doing physically for you. The fact that they do care about you is more important or as important as what they have to do physically."

This was also reiterated by another respondent, aged 93 and currently unable to walk, who felt that the mood of her care worker had a large impact on the quality of interactions with her during a visit:

"It all depends on what mood [carer is] in. Sometimes she's quite nice, nice little girl but as I say she does the job adequately. I think they've got a little bit of a chip on their shoulder some of them. I had an Indian girl one day and she was super, she was different altogether."

The importance of trust was also discussed by many participants. It is evident that trust needs to be developed between care recipient and care worker; the importance of continuity of care is an inevitable pre-requisite to the development of a trusting relationship. This was highlighted by an 86 year old respondent who spoke of the difficulty for her in receiving intimate care without having developed a trusting relationship and how this can negatively impact on physical as well as emotional health as she would delay using the toilet properly until carers had gone:

“Yes they do wash me intimately they say “should we do that, can we do that”. I’m alright now but the first time I was very embarrassed it was terrible especially things like intimate, if I want to go to the toilet. I used stop and hold up because I was embarrassed and so nervous, it’s much better if you know and like them, if you’re used to each other.”

Understanding and incorporating, where possible, the preferences and desires of care recipients was highly valued. The following quote from one family member demonstrates the importance of allowing care workers time to undertake tasks that provided care beyond essential needs:

“They add little things like putting nail varnish on her last week. See mum loves stuff like that and it’s nice that this young girl took the time to do a bit of nail varnish for her. I think she was over half an hour that day because she was putting nail varnish on you mum and that’s what a carer should be doing. Someone who doesn’t care shouldn’t be doing the job if you don’t give the time.”

For many recipients of care, the home care visits were their only face to face human contact in their day, intensifying the importance of this contact and the effect of interactions, both positive and negative, on emotional well-being. Some care recipients valued the positive boost given to them when care workers complimented them on their achievements or appearance:

“When my eldest son comes and he always brings me flowers and they always say ‘ooh you’ve done your flowers nicely this week’ it’s just little things like that that really makes your day.”

“[...] they’re always pleasant to you you know, I mean you sort of, you know, they sort of say, you look nice, you know those sort of nice, you know things. [...] Very fond of all of my carers.”

The emotional bond between many interviewees and their care workers was evident in the expressive way in which they referred to them. This is illustrated in the quote below from an amputee and retired teacher who became visibly emotional when describing how much she appreciated how the support she received enables her to stay in her home, rather than moving into residential care:

“Well I feel very fortunate, I feel very fortunate to have such good care (becomes tearful). I couldn’t manage without; I would have to have gone into a home because I can’t stand at all. I forget that, I was lying in the arm chair over there months ago and I thought I’d get myself a cup of coffee and I nearly got out of the chair, I thought “sit down you silly fool you can’t go anywhere” but no that sort of gives me the freedom to do my embroidery, they are like a breath of fresh air coming in with the news from outside. They’re always polite and nice and they’ve learnt the way round my kitchen.”

Even though respondents may have overwhelmingly positive experiences of their home care they were aware, from stories in the media, that this was not always the case. Many felt that they needed to redress the balance and show their appreciation and praise for the care they received. The husband of another recipient of care expressed gratitude that their experience of care workers had not been negative:

“I mean you read about these people, carers in the paper etc. etc. etc. and hear terrible things, and I know they are very pressured but very fortunately we have never experienced it, we have been very lucky, I am thankful.”

Another 58 year old woman spoke of the closeness she felt with her care worker, likening her to a sister and appreciating the care taken to help her with her appearance, and understanding how this contributed positively to her self-esteem:

“As I say she does, she helps me out a lot and dresses me nice and does tell me when she thinks it doesn’t look right or I’m putting on the wrong thing. She’s sometimes a bit of a bossy boots but then it’s a bit like my dad so it’s alright. She’s lovely, she really is. She’s like my friend, she’s like my sister. I’ve got 4 sisters and they don’t care for me like she does, I’m very lucky. She makes me feel good about myself.”

Professional distance - in the absence of close carer relationships

Although the benefits of a close trusting relationship between carer and recipients were extolled by the majority of participants in this research, it was not the case for all respondents. Many respondents expressed a desire for a more professional relationship with their carers rather than a close relationship. They were happy with a professional and efficient approach and appreciated the distance and degree of privacy that this allowed. However there was also evidence that the possibility of a close relationship was often not achieved due to barriers imposed as a consequence of the logistical organisation of home care rather than through personal choice. The barriers most regularly cited were restrictions imposed on them because of time and irregularity of carers.

The complexity of developing, or indeed not developing a close relationship with carers is illustrated by the son of a 101 year old recipient of care. He recognised that it was possible to build good relationship with care workers, but explained it was his preference not to do so, but also acknowledge that such relationships are reciprocal and sometimes his lack of input has negative consequences:

“The neighbour said that she got a marvellous relationship going with her women. I said ‘no I just can’t, I don’t want to’. [...] At Christmas I didn’t buy them presents or chocolates or give them a drink or offer them a drink, I’ve never offered a cup of tea and I will say thank you or goodbye and they always reward me by leaving both doors wide open.”

Another respondent talked about the uneasy relationship that he sometimes had with the carers involved with his wife’s care. He talked about the awkwardness of having strangers in the house and that although he could talk politely with them it was never going to be more than a professional association: member reportedly viewed his wife’s care workers as people he could speak with, but as acquaintances rather than a relationship that could be likened to friendship:

“Well you speak to them, very loosely, the same as I’m speaking to you. They’re strange people coming in your house but I can talk to them and get a reception as such, they’re that good. It’s not like a friendship or anything.”

One 55 year old respondent acknowledged that his lack of closeness with his carers was due to his reserved personality. He felt that his reserved nature limited the degree and depth of conversation as he did not tend to open up or divulge personal information or problems:

“Well they don’t get long so you could converse with them, yeh really, I’m not one for bleeding out, bleeding my heart out to them so yeh you can have conversations with them and I get on well with them so yeh they’re ok.”

Another male respondent, who received home care after a stroke, spoke of having a positive relationship with his carers, but it had its limits. His expectation of the relationship was one limited to his medical needs rather than a more holistic approach:

“It’s fine, I don’t have any problems. Well I don’t think there is anything I want to confide in them. Apart from medical matters.”

Cultural expectations: communicating need

This research elicited a wide variety of opinion, concern and expectation in relation to care processes, relationships and need. The context within which these elements interact is an important factor in determining the success or failure of the system. Carer’s, recipients and their families do not exist in isolation and their needs are complex and intertwined. The experiences and backgrounds of all of those involved within the caring nexus will inevitably impact on individual functioning and expectation. Within this context a dominant theme was cultural understanding and expectation. Interestingly some respondents cite the different cultural backgrounds of their carers’ as an important factor in supporting their social and emotional needs. Inevitably some respondents conflated ethnicity and personality and it is important to differentiate between the two, however there were also many citations that placed culture or ethnicity as an important factor in their overall experience. Care recipients evidently negotiated cultural differences in individual ways; aside from communication/language issues there was also evidence of sharing knowledge and experience and of cultural enrichment.

It is evident that the strain of home care arrangements can be exacerbated when relationships and procedures do not function in the individuals' best interests. Some respondents in this study described difficulties with communication between their care worker and themselves. The tendering out of care services has resulted in an increase in migrant workers filling carer positions (Schutes, 2011). Although this is not a problem in itself it can, if not handled sensitively and supported by effective and on-going training, lead to difficulties. The family member of one individual involved in this study spoke of the difficulty a language barrier can present. Although carers were not maliciously acting against her mother the respondent expressed anger at what she perceived to be the carer's inability to acknowledge how conversations in a language her mother did not understand were making her feel unsettled and excluded:

"They were coming in also speaking in their own language in front of my mum all the time. I used to pull them up downstairs if they done it in front of me and would say 'while you're in this house you speak English, if you can't speak English then you don't speak'."

It is evident that frustration can build quickly and angrily if allowed to fester. The demand to 'speak English or stay silent' seems an extreme response and although the situation would have benefitted from an intervention before the angry demand was made it is evident that home care relationships need careful planning, consideration and support.

A number of different interviewees spoke of communication problems of some sort or another with carer workers who they felt were not fluent in English, or lacked comprehension skills either when care recipients had difficulty making themselves understood, or had difficulty understanding their carers:

"[...] my regular carers are great and I can't fault them at all but every now [...] they might send someone who doesn't speak very good English, or someone who is a bit slow to understand, who you have to tell them what you require. I'm trying to explain to them what I need, it can be a bit monotonous."

Two other respondents in particular spoke of communication difficulties with their care workers, but stressed how quality of care and a caring attitude could still be conveyed, despite a lack of shared verbal language:

"Well she's Indian I think, she's lovely and ever so caring and she's very very good with what she does. It's a very slight problem with understanding what she says sometimes and she is the same with me but she's lovely, ever so good and I really miss her when she doesn't come. [...] [Would like to have] just time to talk really, I don't know if would help with my present carer because we wouldn't be able to have much of a conversation I don't think."

For some participants there was undoubtedly an awareness of cultural difference when they were discussing their care. Recipients often referred to their regular care workers ethnicity in the context of praising them for their attitude and support:

"She's a big Nigerian lady and she's full of fun and full of laughter."

Although this quote seems harmless enough as it reflects a positive feeling, it is important to understand that the carer may have had a 'fun' personality but this should not be equated with her ethnic origin. The danger of allowing such misconceptions to perpetuate is that such logic could easily be applied in its negative form, so that a carer who may be considered grumpy is such *because* they are Nigerian. It is therefore important for all those involved in the provision of care to be aware, and make provision in terms of training, of the issues and challenges relating to ethnic stereotyping, cultural expectations and the potential for racist language and for want of a better description, 'old fashioned inappropriate thinking.'

Many participants talked about how meeting carers with different ethnic backgrounds had enhanced their understanding of different cultures and this learning process enriched their social experience and made them more tolerant of difference:

"She was a lovely girl from Uganda I think but as she said there aren't any jobs out there for actors and actresses so she was doing this. I said 'do you like it' and she said 'I love it I meet lots of people' and you could tell she did love it, the way she treated you and that and she said can I make you a cup of tea before I go, I said no it was alright. It's just the difference you get. I would ask her about her life at home, it's very different but different can be good."

One respondent, who identified as Christian, described the love she felt for her care worker and how she felt they learned from each other's' differences:

“it was a Muslim lady who came for all those months, six months at night [...] I learned a lot about the Muslim religion as it should be as it should be and how she lives it. How she lives it yes. Uhm and she, oh I loved her absolutely.[...] you know I’d be waking up at 3 o’clock in the morning and you know, and empty my night bag and of course she’d come in and I’d say ‘Well I was awake at three and I wasn’t facing Mecca but I said a prayer with you last night’ [...] she was what I needed at that time to have someone as loving and I mean it would be not be to confide in, but I was so, it was like post-traumatic stress disorder really [...]”

For others questions of ethnicity were irrelevant, they were simply concerned about the level of care they received irrespective of who was providing it:

“No they’ve always been very nice. Whatever nationality they are and you do get different nationalities, I mean I can understand some of them but they are there and they do give you the care that you need. I’ve got no complaints about the care I get.”

Lack of training, stress and pressure - barriers to good care

“Sometimes I may get a carer here that’s very heavily pregnant and they can’t dry me and I know they are hurting and I’m hurting to see them hurting, very frustrating.”

It was evident from some responses that there was a perceived lack of training, ability or motivation from some carers, which was seen to be exacerbated by tight schedules and poor pay. A number of interviewees also perceived a difference between younger and older carers, feeling that younger staff members were more likely to lack experience and training. One interviewee, whose 9 children also helped with her care, felt that younger care workers were more likely to treat them as a “nuisance”:

“On the whole the younger ones. Dignity and respect, no they just treat you like another person that can be a bit of a nuisance at time is the impressions they give you.”

It was noted that a lack of experience was particularly critical in relation to practical tasks or using equipment, even common appliances such as irons:

“[...] I know they haven’t [been trained] because I’ve had so many who’s admitted to the fact that they haven’t had really any training, they’ve only been in the job a matter of a couple of week and this sort of thing and they haven’t had any care experience before they join this company. [...]Of course the younger ones they don’t even know how to use a microwave or anything like that and you get... I get concerned about them sometimes but that’s just the way it stands.”

One participant described how they had had to replace three kettles as carers had repeatedly put their electric kettle on the open gas hob:

“I couldn’t believe it, three times it was, three kettles burned and melted, they were the cordless type so I suppose they didn’t know, but three times!!!”

One interviewee, who had been receiving care in his home for 7 years, attributed perceived lack of training in younger staff to changes in the way that carers are trained:

“That’s another thing the old carers are well trained they go on courses and keep the training up as well but I’m afraid they don’t get the training the old carers used to receive. The new carers coming along, I don’t think they even shadow them now, they were shadowing others to get trained but I don’t think they are even doing that now. I don’t know what training they get if any, it’s very poor – the new ones.”

The respondent below, who had also spent some time in a residential care home, felt that a combination of lack of training and lack of time had a negative impact on the quality of care received:

“I don’t really think they are well trained these girls, although she does go for training because she told me one day she’d got to go for training so they do have training. [...]She knows what she’s got to do and that sort of thing but it’s just that they don’t have a lot of time because they’ve got from here, they’ve got to get to somewhere else all in about half an hour so they are very limited with the time that they are given.”

In addition to the issues of training and experience of care workers, other barriers to care were identified as workers’ physical ability to carry out duties. One interviewee

raised concerns about a carer whose pregnancy seemed to be an impediment to safe manual handling of her late mother, potentially putting both her mother and the carer at risk:

"One came round that was heavily pregnant, had trouble moving my mum because although she was only 4 stone naturally because she hasn't got the use of her legs now, you do have to lift her out of the chair and things, and she couldn't manage on her own. Some [carers] were better than others."

One family member questioned the ability of carers to work independently, recalling a number of occasions where his mother's care workers contacted him with questions, resulting in another family member having to go to help:

"But I think other examples of the carers – we had some carers that every time they were here they would call me because they didn't know what to do. [...] I really don't have... there are some good carers genuinely but they are very few and far between. [...] Whilst I appreciate the carers themselves are not paid a lot, it's the significant amount of money that we are shelling out for this."

Some participants commented on some of their more negative experiences where they observed a general lack of motivation from care staff. They criticised the fact that the time for which they were being charged was not spent solely on providing care. The son of one deaf recipient of care objected to time spent "gossiping":

"Some of them are very strong on being here for half an hour and I know they are standing about gossiping and they haven't started on time and somebody said to me 'oh well they are making a relationship with the patient', 'No they're not, they're outside in the hall gossiping and talking about hair styles' [...]"
(Family member)

Even when carers were seen to be trained and professional, the pressures on the carers that were witnessed such as constant phone calls and restrictions to time allowed with each patient were noted to be detrimental to the care received and the motivation of the workers. This also meant that for some respondents the stress was translated to them and placed a burden on both them and the carers and meant that they felt unable to assert their needs:

“I mean they might be in the middle of dealing with a client and their phone goes off and it’s the office phoning and asking if they can take another one and quite often the carer will say ‘well I’ve still got 8 more to do, as it is I’m not going to finish until 11pm tonight, no I can’t take another one I’m sorry’. They get, some of them of course the younger ones they haven’t got the experience to say no. Some of them come and they look really as though they’ve been pulled through a hedge backwards, their hair’s all over the place.”

One respondent, the only child of a Bexley resident who received care following a heart attack, noted that such pressure on staff not only affects the level of empathy carers have for clients, but can increase the likelihood of mistakes being made:

“I think it’s more about the system than about the individuals because the carers that come in are under an enormous amount of pressure because they are given really rigid schedules to stick to and they have to be in and out in 15 minutes and they know literally that’s what they can spend. That creates problems because there was again, I wrote to the care company about that on the 5th February, her tap had been left running and then once previously before that had been left running all night and then my mum’s on a water meter and the thing about the light it’s just time pressure and that doesn’t give the carers any chance of doing the job properly it’s just in out and you are bound to make mistakes when you are under that sort of pressure all day long. Also I know that the money isn’t great either so you don’t get the quality of care of people coming in who really want to do the job so you get a high turnover of carers then because it isn’t a very highly paid job and people that do the jobs don’t come from that sort of background.”(Family member)

Unmet needs – Loneliness and isolation, facilitating community involvement and independence

“I’ve lived here now for 49 years and none of these people who live around me apart from that man next door who I rarely see and a lady this side, I don’t know anyone else. Several of them have died or moved away. The lady and the man next door are in their seventies anyway and having their health problems and I certainly wouldn’t add to them so I don’t even think about calling on them, do you see, I won’t do that.”

One of the most common themes that evolved from this research was the consistent issue of loneliness and isolation. Many respondents felt lonely, regardless of whether they had a good relationship with their carer, and struggled to access additional services or were not aware of them. Social relationships are most frequently reported as the key factor contributing to quality of life (Bowling, 2012). The EHRC Research Report 79 ('Older people's experience of home care in England') highlighted social isolation as "a key area of human rights that the current system in England does not adequately address" (Sykes & Groom, 2011, p.13). When investigating the experiences of disabled adults receiving care at home, Gibson et al (2012) also acknowledged this deficit in Canada:

"The potential for social isolation described in the accounts suggests a violation of the social dignity of disabled people both on an individual and group level. Isolation and marginalization not only affects an individual's sense of self-worth, but disabled people as a group may be systematically denied their collective dignity when they are treated only according to their physical needs in a 'minimalist mode'. Conceived of in terms of their personal care needs only, disabled people are denied the opportunity to give and receive love, and to contribute to the lives of others as parents, friends, children, relatives, social supports and care providers." Gibson et al. (2012, p. 2015)

Loneliness is known to be an increased risk factor for both physical and mental ill health, with Holt-Lunstad et al (2010) suggesting that people with stronger social relationships benefit from a 50% increase in chances of survival, comparable with the risk reduced by smoking cessation. Wilson et al (2007) found that, within a cohort of older adults, the risk of Alzheimer Disease more than doubled for those who reported feeling lonely. Loneliness is also reported to be a risk factor for increased vulnerability to infection (Glaser, Evandrou, and Tomassini C, 2005); high blood pressure (Hawkley et al 2010) cardiovascular disease (Ong, Rothstein and Uchino, 2012); poor sleep (Cacioppo et al 2002) and depression (Cacioppo et al 2006; Cacioppo, Hawkley and Thisted, 2010). Avlund et al found that engagement in social networks was a strong protective factor against disability in later life (2003).

Many recipients of care and their families spoke about loneliness and the perception that the care they received lacked human contact through conversation, the 'being there' advocated by Lindahl *et al* (2010):

"When mum first came out she actually required 2 carers and the girls would come round and talk amongst themselves, they wouldn't talk to mum."

"[...] there is a lack of care I feel. The girls that do come in, yes I am ok with them but that's personal care really as opposed to active care, physical care even mental care. Occasionally I will get a visitor and if it is a woman [care recipient] will sit there chatting to her, doesn't make sense particularly but she will sit there chatting to them. Between her and I during the day there's no conversation like she will hold with another woman." (Family member)

"It's the loneliness, that's the only thing that we can't do anything about. We can't be here all day every day." (Family member)

"I do find that I get very depressed, I sometimes don't see anybody all day. They have been trying to get me into a day centre but I've been waiting about a year for it."

Some respondents reported an increase in feelings of isolation and reduced function as their ability to move freely within their home was restricted, in some cases reducing their living space to a fraction of what they had enjoyed before illness:

"I can't go out in the garden as I've got steps everywhere."

"as I can't get upstairs now. I know we've got the chair lift but I can't get on it. Well I can't get off at the top, if I got off at the top what would I do? I can't life myself into the wheelchair so husband sleeps upstairs and I've got a phone and last night I was ill and I had to get him up twice, didn't I poor soul. You can dose today (laughs) I don't mind as I kept waking you out of bed. Poor devil I thought I can't stand it he'll have to come down and help me."

"(wife) does need my attention from time to time don't you. She's down here on her own and I'm stuck upstairs"

“It’s very dangerous to get her up and down the stair lift because she’s totally dependent on.... The ambulance come, they carry her up and down the stairs. It’s not safe enough to go on that chair lift.”

“I am more or less limited to just sitting in this chair really.”

As mentioned previously, even when respondents reported being satisfied with their care provision, this did not prevent loneliness, as the daughter of one 93 year old described. She said she that carers had recorded in her mother’s book that they had found her crying on occasion, and that she missed having someone to talk to:

“Well they are good and they can’t do anymore better than what they do anyway. [...]I can’t see that they can improve it really, they do all what we agreed, the care plan. They do what they’re supposed to do [...] You like to chat to people don’t you, you get lonely don’t you.”

For many respondents, regular human contact was limited to home care visits, and some sadly reported a lack of warmth from these interactions:

“They’re not, it doesn’t seem to be part of their instructions that it would be nice if there was some camaraderie between them and I had one that didn’t talk all the time that she was here.”

“I know it sounds awful but when I came round and the carer was here I didn’t think they were treating mum with respect because just throwing the food down and saying “here you are”, I don’t think was very good practice.”

Avlund *et al* (2003) note that “social participation defines and reinforces meaningful social roles through opportunities for engagement, which in turn provides a sense of value, belonging, and attachment” (p. 95). The effect of reduced social contact on well-being was described in many of the interviews. One interviewee in this study spoke of the lifestyle changes his wife had gone through, as her activity level and amount of choice in activities reduced to fit the availability of care to enable her to be active:

“[Care recipient], as I said, has always been a very active person [...] She sits there from the time the girls in the morning go until the time they come back of a night time unless of course I get her up to go, we go out because I can’t leave

her so she's got to come with me and some days she doesn't feel like it, she sleeps an awful lot so she sits in the chair doing nothing. I feel that she really should be doing something."

Some recipients of care had ideas for the kind of activities they would like to be able to access:

"It helps me stay in my home but doesn't help me do what I want to do. Health wise it won't let me."

"[...] And socially, what sort of things do you like to do?"

"Well I'd like to be able to get out to the day centre, give that a try and just meet people."

"now I feel much better in myself but still restricted as to what I can do to be able to do all the things that I did do. I used to sing frequently with singing groups um, church, you know church choir 9 o'clock, the Blue Eyed Choir, veterans club choir where we went to nursing homes, care homes, you know over 60's Clubs to sing and miss that terribly"

While others had not considered that help to get involved with activities outside of the home was something care workers could help them to access:

"Does the care provided create any opportunities or enable you to undertake activities?"

"Well no, that's impossible for them."

"Does the care enable you to be part of a family and a community?"

"Well no the caring system, that's irrelevant to the caring system really."

Transport issues – feeling trapped or isolated

Restricted mobility was cited as the main cause of issues relating to a reduction in social networking and access to other regular events. The lack of suitable and regular transport was seen as a serious barrier to independent living. This barrier impaired their ability to attend appointments, religious gatherings and social engagements.

Cattan (2001) found that older adults in particular wanted to participate in the planning of practical support to help mitigate isolation, such as transport programmes and support to retain existing social networks and access local activities. Avlund *et al* (2004) suggest the provision of transport services to enable elderly people to benefit from social, cultural and religious engagements reduces the risk of mental and physical distress. Strong social networks can evidently mitigate the effects of loss of mobility. In the research undertaken by Vernon and Qureshi (2000) with disabled care recipients, being able to access activities outside of the home, as and when the care recipient chooses, was listed as "one of the most critical factors in determining one's quality of life" (p.262). This was echoed by one recipient in this research:

"I manage to muddle through on my own to be honest. My main issue really is transport which isn't helping me live but it's getting from A to B that's the main stumbling block at the moment, I'm sort of trapped."

Many of the respondents talked about the services they valued highly since their mobility was restricted such as online shopping, mobile hairdressers gardeners, cleaners and taxi services. However, the impact of Government restructuring and cuts had meant that many of these services were now not funded by the Local Authority or were limited and this was negatively impacting on their happiness and well-being. For some care recipients, their ability to continue with a cherished personal hobby was also extremely important for their quality of life. The research of Gibson *et al* (2012) suggests that "living outside of an institution did not in and of itself afford people opportunities to leave their homes, interact in their communities, or participate in social and civic life" (p. 215). As Gibson *et al.* (2012) state, "enabling the dignity of individuals requires the opportunity to engage in meaningful relationships, activities and occupations outside of the four walls of a dwelling" (p.216). One interviewee with Multiple Sclerosis and Bipolar Disorder spoke about missing the theatre, an activity made difficult for her because of mobility difficulties. It is interesting to note that many of the participants, although talking passionately about the loss of social opportunities many respondents seemed unaware that they had a right to social and civic participation:

"Can't think of any really, no I'd like to go to the theatre sometimes, you know perhaps to the Orchard and erm, but even if I got a taxi I've still got to get out

and it's a bit tricky. [...] It's not a top priority for me; it's not anything but erm. That's about the only thing that I do miss, I miss the theatre."

An 85 year old widow told us that lack of suitable transport meant she was unable to continue to attend church – not only a means to keep her faith, but also a sustaining social network:

"I used to be [religious] more than I am now I can't get out. I used to go to church regularly up to probably 4 or 5 years ago. I find it difficult to get there now so.... It's gone by the board a bit and they haven't taken much interest in me, no one seems to care very much if I get out or not."

Home care as respite for family carers

"Yes I'm very grateful for them to come knowing that they are going to come along, they'll get [wife] a cup of coffee if perhaps I don't feel like it."

It is evident from this research that the full-time, or part-time, family members actively involved in the care of family members were under huge stress and they all expressed some degree of isolation. Though they appeared generally more critical of the services received than recipients of care, family carers did express appreciation for any support they received from professional carers. A qualitative study with statutory and voluntary sector health professionals exploring their understandings of the needs of carers found that:

"Carers want services and staff that listen to them, value their knowledge and expertise and treat them as partners, especially in the assessment process. Carers need teams and services that are pro-active, dependable, consistent, responsive and family and community orientated. Carers need respect for their personal values and cultural beliefs, together with professionals that acknowledge carers' established routines and ways of caring. Carers need professionals to provide hope, information and positive ways of coping. Carers need services and professionals to recognise their other commitments, such as employment, education and child care. Carers need services that identified what to do and who to contact at times of crisis." (Gray et.al. 2008:385)

Some of the more negative elements of the homecare service in relation to the impact on family members involved in the care of loved ones, such as the impact of care worker lateness resulting in family members being late for work, or having difficulty planning their day around care visits, have already been discussed. Although the 'complaints' seem extensive the overwhelming majority would rather have the option of homecare in spite of the need for improvement. The most positive comments were related to the provision of respite and time allowed for self-care:

“so because I’m the main carer once he is up and dress that gives me the time to look after myself”

This need for respite was even more necessary in view of the fact that a large number of family members described a reduction in their usual activities and social contacts resulting from caring responsibilities. Reduced activity is known to be both symptomatic of, and a risk factor for, depression, which the interviewees below reported:

“I do feel that we are very isolated, I mean I just don’t do anything that I used to do at all and nor does [care recipient] do anything that she used to do. We sit here virtually and watch the gogglebox most of the time which is not good at all. I suppose without a doubt I do get quite depressed sometimes.”

“And I think the other challenge is, I haven’t had, I haven’t seen friends, I rarely go out because it would actually be nice for me to go away for the weekend but the prospect of trying to get carers to come at the weekend, I just don’t feel comfortable with them, I think that’s the other thing as well.”

The impact of respite is important on both physical and emotional levels. There are many elements to the care provided both physical and emotional and this responsibility is both significant and challenging. The work of carers involves tiring physical expectations as well as emotionally draining elements. The spouse of one of care recipient, who also receives home care himself, spoke of the positive impact of his wife’s care workers on his emotional health. He described additional actions taken by the staff that communicated care for him, and not just his wife:

“No, I think the biggest thing is, for me, I just don’t know how I would cope without [wife’s care service] and certainly from the point of view of stress, I think I will probably going into the depths of depression quite frankly if I’m perfectly honest. But having them come in and although again they come in for Win, but they always ask if I want a cup of coffee. They don’t have to because they’re not my care, I have my carer once a day but they are always helpful like that, they will do anything. If for some reason my carer has forgotten to do my legs, which has happened, my fault as much as hers because I should know whether my legs want creaming or not – and if there’s a new one, they don’t always know and if that happens I know one of [wife’s] girls, I only have to say ‘any chance’ and I know they will do it. That’s why I’m really – I’m not only pleased, I’m pleased with the girls, I’m pleased with the company that they work for [...].”

It is evident that the responsibility of caring for other family members, although rewarding on many different levels, can be a very stressful and exhausting responsibility. According to research by Shah, Wadoo and Latto (2010) in situations where both carers and users felt that the basic needs of care recipients were not being met their dissatisfaction with professional services caused them distress and anger. The feeling of being ultimately responsible for the care of their family member can be seen as a ‘carer burden’. The ‘burden’ of caring takes time and energy, it involves often complex processes and negotiations with care providers and significantly it is often ‘hidden’ or ‘invisible’ certainly at least in terms of the nation’s GDP. One family member spoke of the physical impact of the care they provided:

“I’m exhausted; I’m always fairly near the edge of the emotional precipice, very emotional.”

Lack of timely and accurate information and advice for family members from multi-service agencies was also raised as an issue by several family members. Lakeman’s (2008) research in Dublin described the ‘load’ that participants felt was placed on carer’s from first contact with services, stating that “a common thread across all respondents was the need for basic respectful engagement and ready access to advice and help if needed” (Lakeman 2008:209).

The inadequate communication and involvement of carers in the care provision process, as discussed in previous sections often leads to frustration and delayed access to appropriate assistance:

“I found it quite difficult trying to find out what was available and that would have been helpful. Originally before my mum started having formal care I knew that she was getting older so I phoned social services to ask them if there was anybody who could come round and assess the bungalow for hand rails and stuff like that which I was quite prepared to pay for but I just wanted some professional advice on what could be done to help my mum’s living and I was told quite bluntly that I didn’t qualify for any of these services so they couldn’t help and I just didn’t know where to go for assistance.”

“[Interviewer] So they didn’t sign post you to Age UK or anything like that?”

“No, but then I phoned Age UK and I guess it’s just who you get, because I phoned them and was asking about whether they could help and again they said I don’t deal with this, this is outside my area of expertise. I kept getting barriers all the time and I didn’t really know what was available and where to go.”

One recipient of care who worked until a stroke left him unable to walk suggested a centralised source of information, a “checklist”, to inform care recipients and their families of what they may benefit from and/or be entitled to:

“What you don’t get is a list of all these [services on offer]. I mean one thing we’ve now got is 2 dustbins because one of the carers said ‘did you know that you can have 2 bins because you’ve got 4 pads going in everyday’. I phoned them up and got it a couple of days later. The one that was with her said ‘well I’ve been working here for 5 years and I never knew that’ so nobody tells you, there’s no checklist of all these things. I went round the doctors and it said a notice from Age UK, that they provide a Chiropodist service; we just looked up the yellow pages and go one. You come out of hospital full stop, Carewatch come round and that’s it. You’re not aware of anything else that’s available; nobody provides a checklist of all these things. I mean, even the doctor doesn’t come round, not as a matter of course just to see you or anything.”

Within the field of mental health Jeon et al recognised the importance of reducing the burden of care on friends and family members for “continuity of care, prevention of illness both for caregivers and care recipients (relapse prevention).” Their recommendation was that the “provision of appropriate and timely respite care should and must be addressed, as a potential critical component of effective mental health service provision in sharing the burden of care and reducing family vulnerability” (2005:304).

Feedback and complaints

“If you don’t make a fuss they won’t bother.”

Most respondents felt that they knew how to give feedback or complain about their care service should they wish to do so. However, many of the respondents appeared reluctant to criticise the service, expressed sympathy for the shortcomings of the service, and/ or felt there was little they could change, possibly because of their own condition, lack of funds, or perceived lack of alternatives. Respondents also had mixed experiences of complaining about services. The respondent below complained about inconsistencies in the care provided to her late mother. She described how her initial complaint letter was not responded to, and a meeting was allegedly only arranged after she called the service. In the quote below she describes her experience of the arranged meeting, and what it meant to her:

“We had a meeting altogether, the manager of the care home didn’t feel that it was important enough for her to attend and sent a deputy, the deputy was 15 minutes late and hadn’t been briefed so didn’t know what the meeting was about or why she was there and she didn’t take any notes either and I haven’t had a written reply since and that was on the 17th February.”

Others felt that promises made by service managers were not kept:

“No, the manager was coming but she hasn’t. She said she’d ring me up and say that she would come and talk to me but she hasn’t come so I’m just waiting for somebody because sometimes on a Sunday I’ve had to ring up and ask when is the carer coming because it’s got later and later because I have a different one on Sundays. Then she did say well I will come and see you but they haven’t come.”

The feeling of a complaint 'not making a difference' was a common theme amongst respondents:

"I've spoken to other people that belong to different companies and they have the same difficulties as I have with [care provider] so I think I'm not going to improve on what I've got so I need to make the best of it. It's not easy, only once or twice I've phoned up and said "I've been up since 5.30 this morning and it's now quite late, I haven't had a carer come to me at all this morning. I do understand that you're probably busy with one thing and another but this is a person at this end not part of the machinery"

"But as I say, it's, I can't have any more time, that's what the council have said so really it doesn't matter what they say or I say, the council said I can just have the hour in the morning and the hour in the evening that's it."

"Of course as I say to me 45 minutes was not enough time to have a bath. Yes she took it on-board, she understood what I was saying but because of the law, now whatever law she was relating to I don't know, she wasn't able to do anything about it."

One respondent who described the problems caused by care workers arriving late or not at all said that when his care was unsatisfactory, he kept in mind the option that he could vote with his feet by changing to another service provider:

"Sometimes I feel so upset with them and think should I do with another firm that does it, I've have thought about it at the back of my mind. I know I can do that."

In contrast some experiences had elicited more positive responses in relation to the providers of care:

"Oh yes they do [listen] because when we spoke to this lady called [...] it had some sort of repercussion effects them all I think, don't know what it was but yes she's determined to sort it out oh yes."

One care recipient, who reported being "thrilled" with the care she received, suggested that not complaining about problems would result in being seen as "easy going" and receiving a lesser quality of care:

“So they do know me, they might cringe when I call up (laughs) I don’t know. It’s no good sitting quietly if you’ve got a... it’s no good letting it pass because they think then “oh she’s easy going and won’t mind”. I don’t say that’s how they think but I’ve known someone who works for [care provider] and she says that’s how they think, if you don’t make a fuss they won’t bother.”

Care recipient recommendations

“they have not been into this house to assess it for their staff and they should be here assessing the whole place for their own staff as well as for..... and to know me as a person and not just a name on a page.”

Finally, care recipients were asked if the service they received could be improved. Responses have been categorised into dominant groups with two main headings: ‘time-keeping’ and ‘quality and scope of care’ reflecting the most numerous responses. Other comments have been differentiated under the headings - ‘nothing to improve’ and ‘ambiguous/neutral’ responses.

1. Time-keeping

As discussed in section 9 the consistency and suitability of timings for care visits was the source of much consideration and concern. It was also one of the main complaints that both recipients of care and their families raised. In summary, respondents told us how care worker time-keeping was often the cause of serious disruption that had affected their social and working lives, as well as creating anxiety. The inappropriate timing of appointments was a key area that respondents felt needed improvement. The most frequent comments/recommendations were as follows:

“Fair and regular times for visits.”

“It would be ideal if they could really stick to a timetable”

“Time- keeping is really the only one.”

“So like consistency of timings.”

“Just the time they come and the quality of care when he comes and they’re all good.”

“Coming at the times they should come, being reliable and continuity.”

2. Quality and scope of care

Many respondents spoke of the improvements they felt could be made to how care workers interacted with them, suggesting that further training might be beneficial to improve quality of care. It was also suggested that the length of time given to carer appointments be reviewed so that all elements of personal and emotional care could be adequately provided. Other respondents wanted to see support available for a

greater range of activities, allowing care recipients to 'top-up' care allowances to enable them to access more care to improve quality of life. The following quotes are representative of the recommendations relating to these themes:

“Regular carers that you have that you can engage with that definitely not just any carer but someone that understands you being visually impaired and can chat away. [...]”

“Just time to talk really.”

“I just need more time, it’s always such a rush, it puts you on edge, they need to allow more time.”

“Nothing’s perfect but [care provider] is as good as it could be if the office staff were improved and all the carers that come got the proper training like they used to have but they don’t get now.”

“They’re all individuals so these people they employ need individual training.”

“Only as I say I feel that.... [care recipient] was always an active person, cycling, swimming every week, but she’s not doing anything. She should, I think, be doing something.” (Family member)

“I think it could be improved by being more joined up with GP’s, hospital, district nurses and I think it could be.... At the moment it just seems that it’s all about the money and just having rather than the care just getting in, getting out and doing the bare minimum when it’s people’s lives you’re dealing with here. Giving people the option that if they have got funds to pay more and to get a better service that they can do that as well and have some choices.” (Family member)

3. Nothing to improve

Some respondents were currently happy with their service or felt that problems they had experienced in the past had been satisfactorily resolved and they now felt that they didn't have any suggestions for improvements:

"No I'm quite happy with the way it's all going at the moment."

"I don't think it can really [be improved]. I don't think it can because I feel sure that if I needed any more aids to help me live, I've only got to apply to the right department and they'll send someone to see me."

"Not at the moment [...]"

"I don't think it could, it's the timings that are not quite right but I think I've sorted that out now."

"I can't see that they can improve it really, they do all what we agreed, the care plan. They do what they're supposed to do, it's just a couple things that went wrong once and I just rung them up and it's not happened again."

4. Ambiguous/ neutral responses

Some interviewees were ambiguous about the quality of the care they received, seemingly taking the view that change came with a risk of care worsening. Bowling (2002) warns health providers against complacency where service feedback, from older adults in particular, is positive or neutral, suggesting that older adults are more likely to consider themselves fortunate for receiving greater access to information and care than their parents. Some of the responses from participants in this research could be seen to be in this category:

"Well all I can think of is it could be a lot worse."

"[...] sometimes if you stir things up too much things get done and they change the firm that's doing it and you could go out of the frying pan into the fire because their carers may not be good."

“[...]It’s no good listening and then going away and doing nothing because that’s not going to help anybody.”

RECOMMENDATIONS

Although satisfaction with the home care service received is, according to this research, high, there are evident areas that should be a focus for improvement. This report has highlighted a number of areas where home care is not meeting the needs of elderly and/or disabled people in Bexley.

This section therefore contains recommendation, by the authors, based on the findings, for actions that could be taken to ensure that home care in Bexley meets more than minimum standards and provides the best possible quality of care. These recommendations refer specifically to providing individuals the support they need to stay at home. The recommendations are not in order of priority and are therefore all of equal importance.

1. Facilitating access to community networks: reducing isolation

The need for companionship is very evident from this research. Although time for conversation/social interaction is not specifically in the remit of paid carers they are working with often very vulnerable and evidently lonely individuals. The carer role needs to reflect this reality by supporting paid carers to demonstrate compassion and kindness during these necessary human interactions. Beyond this there is an evident need to address the important issues of loneliness and isolation with a wider more coherent approach. The health advantages of reducing loneliness and maintaining existing social networks are well-documented. The following would help maximise this benefit:

- A multi-agency group should be established to provide better and more informed care choices. The remit of which should be a focus on practical outcomes in relation to transport, housing, health and social care.
- The provision of transport schemes to increase access to meaningful activities outside the home was given a high priority by most of the participants in this research.

- Commissioners should ensure that provision for emotional support is part of standard care packages and that options include access to talking therapies, befriending and mentoring.
- A multi-agency approach should also ensure that links to Social Prescribing for isolated clients is established and maintained in order to provide access to community networks including libraries, reading materials, films, voluntary groups and local age related groups/activities.
- A one-off information giving visit would be helpful in reducing isolation and loneliness (McEwan et al (1990, in Cattan et al. (2005))).
- A useful contacts list with useful telephone numbers, voluntary organisation information and relevant websites for all family members.
- Commissioners should explore provision of social groups and befriending services, tailored to the needs and preferences of the individual for both family carers and recipients.
- Care agencies need to have regular communication with commissioners so that they can highlight those most at risk of loneliness. Commissioners should incorporate partnership working with volunteer organisations in order to address those issues and provide support to this vulnerable group.

2. Maintain high monitoring standards

Commissioners must ensure that care providers are maintaining the highest standards of care. Missed care and lateness were common complaints among recipients, along with lack of carer consistency, resulting in reduced quality of care and potential safeguarding issues. Health needs change rapidly among older and disabled populations, but these developing needs were not being assessed or met far too frequently. The following actions are recommended:

- Regular face-to-face reviews with care recipient and family members in order to reassess care plans, provisions and ensure satisfaction.
- Minimum standards of training for care workers and additional training provided when skills gaps are identified.

- Home Care provision should link into wider policy initiatives such as the loneliness group and the Older Persons Strategy in order that recipients receive a joined up service. There should be ongoing monitoring to ensure that home care is incorporated into the wider strategic framework for supporting the care needs of residents.

3. Improve choice of type and level of care

Respondents in this study felt that their input into the type and level of care they received was limited. People receiving care in their homes should be able to choose options to suit their needs and preferences. To achieve this, the following steps are recommended:

- Individuals and families should be more involved in the organisation of care and the on-going care plan.
- It should be made easier for clients to complain, so that any issues are highlighted earlier. An allocated contact at the council is recommended to improve this.
- Consistency of carer and timings allows clients to build relationships with care workers, allows care workers to learn the routines and preferences of the client, and provides reassurance that plans can be made for the day. More changeover time could be built in to care worker schedules to protect against lateness, and communication needs to be improved when care schedules are affected.
- Flexibility in care provision should be allowed, so that care provisions can adapt to the changing needs and lifestyles of care recipients, with regular reviews of needs.

4. Improve information on other services

Care recipients reported diverse experiences of how information on other services was provided. Commissioners should ensure that clear guidance and pathways are provided to help care recipients access complementary services

- Care recipients should be offered the opportunity to ‘top up’ existing care packages with private funding, to increase care without losing consistency of care provision.
- Provision of a ‘check list’ to ensure all relevant public and voluntary sector services are being accessed should be part of a regular review process.

5. Smooth transition from hospital to home care

Some participants described difficult experiences of leaving hospital to return home to receive domiciliary care. The following would make this easier:

- Timely assessment for and provision of enabling equipment in the home, as well as adaptations when appropriate.
- Improved communication to ensure care recipients and their families are fully involved in care plans, know what to expect from whom and when so that there is a clear patient care pathway established.

6. Effective Communication and continuity of care

In order to ensure that the experience of Home care is a positive one, clients must feel that they are important, listened too and fully informed about their choices. Care workers must also ensure that communication is clear, accurate, effective and professional. The importance of effective communication and continuity of care moves beyond meeting basic physical need, workers should develop relationship founded on trust, compassion, knowledge, experience, cultural awareness and empathy, all of which are essential to ensuring that the experience of Home Care is a positive one.

- Wherever possible priority should be given to ensuring continuity with regards to care staff. Clients should have a small designated team of carers to ensure all sickness/holidays are covered by know workers. This is essential for building a trusting relationship with care workers especially when undertaking intimate tasks and identifying changes to need or deterioration in health. Ensuring continuity also allows clients to have some agency over how care is carried out as they would,

and should be able to 'train' staff in how best to deal with their specific needs and preferences.

- Care providers must ensure that care-workers are aware of the need to communicate essential information to clients and their families as quickly as possible. Structures and processes need to be improved and continually reviewed in order to share such information.
- Care providers must ensure that care-workers undertake regular training and monitoring in communication skills ensuring that all interactions maintain dignity, respect and the necessary safety requirements. An important element of the communication between carers and client/client's family is ensuring that workers effectively explain unfamiliar terminology and processes so that all parties are fully informed about the arrangements for their care.
- Care providers must also ensure that care-workers undertake training to ensure that the service they provide and the interactions that they have with clients is culturally appropriate and sensitive to their individual requirements.

7. Further research and development

This research has highlighted the very evident need for further research into one of the most dominant themes to emerge from the findings – the extent and effect of loneliness and isolation in this highly vulnerable population.

- Further research should be undertaken on the relationship between isolation, loneliness and depression/mental ill health to evaluate the current extent and need for additional resources/support amongst those in receipt of home-care in Bexley.

For further information please contact the author via Healthwatch Bexley: info@healthwatchbexley.co.uk

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Appendices

Appendix 1 - Abbreviations

CQC - Care Quality Commission

CSCI - Commission for Social Care Inspection (now disbanded)

DP - Direct Payment

IB - Individual Budget

PB - Personal budget

SCIE - The Social Care Institute for Excellence

Appendix 2 - Web-based resources

'Find Me Good Care' is a website run by the Social Care Institute for Excellence (SCIE) which aims to provide adults in England with assistance in finding and funding care services in the home and in residential settings.

<http://www.findmegoodcare.co.uk/>

The Scottish Care Inspectorate provides a similar services <http://www.scswis.com/>

... while the Care and Social Services Inspectorate Wales <http://cssiw.org.uk> -

provides information through the UK-wide independent Good Care guide website:

<http://www.goodcareguide.co.uk/>

In Northern Ireland care services are provided by the Department of Health, Social Services and Public Safety, <http://www.dhsspsni.gov.uk/> which is currently implementing the outcomes of its consultation 'Transforming Your Care'

Appendix 3 - Domains of outcomes: Malley and Netten 2008

- *Personal cleanliness and comfort:* Being personally clean and comfortable, dressed and in bed or up at preferred times.
- *Social participation and involvement:* Emotional support, general social contact and community participation.
- *Control over daily life:* Able to choose what to do and when to do it, having control over daily life and activities.
- *Meals and nutrition:* Having a nutritious, varied and culturally appropriate diet with meals at regular, timely intervals.

- *Safety*: Feeling safe and secure, including feeling free from fear of abuse, falling or other physical harm and fear of being attacked or robbed.
- *Accommodation cleanliness and comfort*: The living environment is clean and comfortable.
- *Occupation and employment*: Sufficiently occupied in meaningful activities whether it be formal employment, caring for others, unpaid work or leisure activities.
- *Living at home*: Enabling people to live in their own homes.

Malley and Netten 2008

Appendix 4 TOPIC GUIDE

PERSONAL INFORMATION

(Questions 1-10 will be asked in a pre-interview telephone call)

1. How would you like to be addressed?
2. What is your gender: Female Male
3. How old are you? (in years)
4. Post code: (first 3 digits only)
5. Which best describes the type of accommodation you live in?
Own home with no mortgage
Own home with mortgage
Owned sheltered accommodation
Rented privately
Rented from council or housing association
Rented sheltered accommodation with warden
Nursing / care home
6. Do you have a disability? Yes No
What type of disability do you have?
7. Do you have a partner? Yes No
If Yes, what is your partner's gender? Female Male
8. What is your ethnic group?

9. Do you have a religion? Yes No
If Yes, what is your religion?

10. Can you tell us about your life -? (e.g. education, marital status, children, work life, hobbies)

SERVICE PROVISION

11. How long have you been receiving care at home (approximately)?

12. What kind of activities do you get help with?

- Getting out of bed
- Washing / Bathing / Showering
- Getting dressed / Undressed
- Help with taking tablets
- Preparing and/or heating and serving food
- Going to bed
- Help with toileting
- Help with physical activities
- Other (please explain)

13. How much home care help do you get ...

- a. per week (days)
- b. per day (number of hours/minutes)

14. Who arranged this home care for you?

15. Did you have a say over the help you receive?

16. Do you think the help you receive covers your care needs at home?

17. Were you or a family member able to choose who supports you at home?

18. Do you have the same carer every time you receive care?

RELATIONSHIP WITH THE CARER

19. Would you say you have a good relationship with your carer at home?

20. Do you feel you are able to confide in your carer in order not to feel isolated?

21. Does the care provider make you feel recognised and valued as a person?

22. Do you think your carer treats you with dignity and respect?
23. Do you have choice over the time that care happens for you? (times of eating, bathing, getting up or going to bed etc)?
24. Do you think that the carer is well trained (interviewer to lead on cooking, personal care etc)

IMPACT OF CARE ON QUALITY OF LIFE

25. Does the care provided help you feel safe and secure?
26. Does the care provided help you remain in your home and do what you want to do?
27. Does the care provided create any opportunities or enable you to undertake meaningful activities?
28. Does the care provided increase your mobility and physical activity?
29. Does the care enable you to be part of a family and/or the community?
30. How does the care you receive make you feel about yourself? (in respect of your quality of life and well-being)

VIEWS ON QUALITY OF CARE

31. Overall how would you rate the quality of care you receive?

Very good Good Satisfactory Poor Very Poor

Could you give us examples of good quality and bad quality care?

32. Are you able to provide feedback to the provider on the care you receive?
Please explain

33. Do you know how to complement / complain about the service you receive?
Please explain

34. Do you feel your carer and other professionals involved in your home care respect your privacy? Please explain

35. Do you have much contact with the Council about the care you receive?
Please explain

36. Do you feel that your views were taken into consideration when the social worker came to talk to you about the help you might need? Please explain

37. Did you feel that this would meet your needs? Please explain

38. Do you receive any other help you receive on a regular basis apart from home care (for example, from wife/husband/partner, friends, relatives, neighbours, or others)? Please explain

39. Are they involved in your care? Do they communicate with your carer?

40. Do these people need support to provide care for you?

41. What other services do you access in your area?

Please tick all that apply:

- Community transport
- Library/Community Centre
- Handyman service
- Grocery delivery service (e.g. Tesco)
- Other (please explain i.e Church/Religious Groups/Lunch Club)

42. Are there any other kinds of help which would help you to live more independently?

RECOMMENDATIONS

43. How could the care you receive be improved?

44. Is there anything else you would like to tell us about the care you receive at home and how it improves your quality of life?