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“It just happens’. Care home residents’ experiences and expectations of accessing GP care.

Abstract

Background: Care homes provide personal care and support for older people who can no longer be supported in the community. As part of a larger study of integrated working between the NHS and care homes we asked older people how they accessed health care services. Our aim was to understand how older people resident in care homes access health services using the Andersen model of health care access.

Methods: Case studies were conducted in six care homes with different socio-economic characteristics, size and ownership in three study sites. Residents in all care homes with capacity to participate were eligible for the study. Interviews explored how residents accessed NHS professionals. The Andersen model of health seeking behaviour was our analytic framework.

Findings: Thirty-five participants were interviewed with an average of 4 different conditions. Expectations of their health and the effectiveness of services to mitigate their problems were low. Enabling factors were the use of intermediaries (usually staff, but also relatives) to seek access. Residents expected that care home staff would monitor changes in their health and seek appropriate help unprompted.

Conclusions: Care home residents may normalise their health care needs and frame services as unable to remediate these which may combine to disincline older care home residents to seek care. Care access was enabled using intermediaries -either staff or relatives-and the expectation that staff would proactively seek care when they observed new/changed needs. Residents may over-estimate the health-related knowledge of care home staff and their ability to initiate referrals to NHS professionals.

Key words; care homes • general practice • health service access • secondary data analysis

INTRODUCTION

There is a range of provision in England for those older people who can no longer be supported in their own homes because of the complexity of their needs which includes supported and extra care housing to care homes with (and without) on-site nursing and nursing homes where registered nursing staff are on duty at all times.[1]. The context for our research is care homes which deliver personal care and support to older people but who do not have on-site nursing care. Residents in these types of care homes rely on visiting doctors (both primary care practitioners and specialists), community nurses and therapists for access to health care and referral to specialist and secondary care services. General practitioners (GPs) are especially important in the care of older people as in addition to their role in the assessment, diagnosis and treatment of illness they provide the link into other community and hospital-based health and social care services.

Access to primary care is a major policy interest of the successive UK administration's as it is a mechanism to reduce hospital/emergency department admissions. Difficulties in accessing a GP are linked with visits to emergency departments and the creation of the 7 Enhanced Health in Care Homes Vanguard in England recognises these problems [2]. Problems of access to general practitioners and other services for care home residents remain a source of concern as do issues of quality of care and levels of provision [6-8]. The regulatory body (Care Quality Commission standards 1 and 2) require care homes to facilitate access for residents to the health services they need [1]. Achieving this objective is perceived as problematic from the perspectives of both care homes and general practices as there are a range of ways that this may happen. Residents may remain with their 'own' GP, the one they were registered with before relocation to a care home or register with locally designated practices [3,4]. As such, most care homes, 85%, work with more than one practice [5]. Similarly, there are a range of service delivery models whereby General Practitioners, discharge their responsibilities for providing primary medical care to care home residents. These may include visiting specific residents in the home on request as they would provide a home visit for someone living in their own home or the provision of regular clinics in care homes which residents attend as appropriate. [6].

It is recognised that there is a lack of integration between care homes and other components of the health and social carescape. There is a body of research with a focus upon developing models of care delivery and working that integrated all the elements of primary, secondary and social care services with care homes. Evidence from a review of effective provision of health care for older care home residents highlighted key elements in the successful provision of NHS services to this population. Two of these elements focussed on contractual and service delivery expectations. These focused upon the specification and delivery of age-appropriate services and the development of financial and contractual mechanisms to specify a minimum service that care homes could expect to receive. However, the third component emphasised support to develop relationships between staff working across the different sectors via activities such as shared learning between NHS and care home staff. These elements are not mutually exclusive but interlinked and are also highlighted in studies that have focussed upon specific issues in the care home context such as end of life care, continence, falls and prescribing. [7-10]. The 7 Enhanced Health in Care Homes vanguards recognises the lack of integration across sectors and focuses upon addressing care, financial and organisation barriers to the delivery of effective health care to residents [2].

Access to primary care for older people remains an issue of concern for older people regardless their place of residence [11-15]. Older people are one of the groups identified as having poorer access to health care with research emphasising the barriers to access as organisational, geographical and socio-cultural. The model developed by Andersen [16] is one approach to understanding the decision-making underpinning the decision to consult a health care professional/services. The most recent manifestation of the model proposes that the decision to seek help from a GP or other health or social care service is the outcome of three sets of factors: precipitating, enabling and need at both the contextual and individual level. At the individual level need for health care includes perceptions of health status, illness/symptom severity and diagnosed conditions. Predisposing factors include socio-demographic characteristics that can also include social factors such as networks and relationships which can support (or inhibit) access to care. Enabling factors include the organisational arrangements for health care (free at the point of delivery like the NHS) and the characteristics of the locality where the individual lives (eg urban or rural, deprived or not deprived).

In debates about service provision and access to primary care the voice of the older person is largely absent, even more so for those living in care homes. There are remarkably few studies that are focussed on life in care homes [17]. A review of living well in care homes identified 29 studies of which only 3 were from the UK and none reported on residents' experiences of accessing health and care services [18]. Notions of 'home' among nursing home residents were evaluated in a systematic review of 17 studies across 7 countries (not including the UK). Although autonomy and control emerged as an important theme in the review this did not relate to service access decisions. The authors do not dwell on how comparable the definition of nursing homes was across studies [19]. A study of 4 nursing homes in The Netherlands examined the concept of home from the perspectives of residents, relatives and care workers. Facilitating care access was raised by staff and relatives but not residents [20].

How does the context of living in care home relate to access to GP services by older people? Although there have been a range of care delivery based intervention studies based in care homes the actual process whereby residents access general health care services have been little studied. Condelius and Andersson [21] applied the Andersen and Newman behavioural model of health care access [21A] model in a qualitative study examining the views of next of kin on health care access for relatives who had died in care. The Andersen and Newman model conceptualises use of health care as the outcome of the interplay between three sets of factors: need, predisposing and enabling. Need factors relate to physical or mental health problems or illnesses; predisposing factors relate to demographic type factors (age, gender, marital status) while enabling factors relate to things which facilitate service access (e.g.. income)

The use of Andersen and Newman conceptual model in a qualitative study is rare as the model is most often used in a quantitative paradigm [21B]. Condelius and Andersson [21] focussed upon enabling factors in their study and highlighted the facilitative role of the next of kin in both supporting access to care but also for monitoring the quality of care provided. These authors argue that for vulnerable elders the next of kin can be a powerful factor in enabling access to good quality care. They also demonstrated the importance of how care was organised within homes in terms of named care staff for residents, levels of staffing and the routine of the home as important enablers of care access. As part of the APPROACH (Analysis and Perspectives of integrated working in Primary Care Organisations And Care Homes) study [22-24] this paper explores care home residents' experiences of accessing GP

services using the Andersen and Newman [21A] model by the reanalysis of interview data collected initially to investigate their experiences of integrated care.

METHODS

The APPROACH study explored how care homes worked with the NHS, and how different ways of organising the delivery of health care affected the experience of residents (and staff) in terms of health care access [22-24]. It was a longitudinal mixed-methods study which included a quantitative survey of service provision to care homes and case studies of six care homes in three different study sites. The homes were selected because they exhibited different models of working with the NHS and presented social and geographical variation: a deprived inner city area in the South East; a suburban town; and a mixed urban-rural coastal area with pockets of affluence and deprivation. Three of the care homes had both residential and nursing beds which were separate in two homes (on different floors) but mixed in the third. In these homes our focus was upon the residents who were not in the nursing part of the facility, and associated staff and procedures. The size of the care homes ranged from 29 to 87 beds; none had safeguarding problems, and all had been assessed by the regulator (Care Quality Commission) as providing average or above average care (the terminology for inspection has changed since the study was completed). Three of the care homes were run by large care home organisations, two by not-for-profit groups and one was privately owned.

The case studies included interviews with residents, staff and relatives as well as a review of residents' care home notes to capture service use. Our data is derived from the semi-structured interviews with residents, conducted at baseline and at 4 and 8 months, about their perceptions of their health care needs, their access to services and their views about how NHS and care home staff worked together. Interviews were undertaken by HMa, HM and SD. The topic guide was linked to the study focus on integrated working between health care and care home staff (see box 1) but discussions with participants about what services they use and how access to those was facilitated yielded explicit details of their role in this. For this examination of service access we only use data from the baseline interviews with residents as these were the fullest. We had thought of examining narratives of service access longitudinally but the data were not of sufficient depth to support that analysis.

Interviews were recorded (with permission) and transcribed verbatim. For our initial project, we used thematic analysis undertaken by two researchers (CV and HM) after each transcript had been read independently by both researchers. This analysis identified three key themes (a) age, health and wellbeing; (b) accessing care and (c) the social context of living in a care home (see 24). Here we present a reanalysis of the baseline interview data using the Andersen and Newman [21A] behavioural model of health care access in the care home context as the organising analytic framework. The data/themes identified were re-examined by CV using a content analysis approach to directly identify the presence/absence of key attributes of the Andersen and Newman model [21A]. In terms of health care needs we have details of pre-existing conditions from care home records as well as participants' narratives about their own health. Enabling factors focused upon the context of the home and the availability of relatives/staff as advocates for care access whilst predisposing factors focused upon the propensity of the individual to seek help for identified needs which linked with their evaluation of their health status and expectations of health in later life. Need for care was operationalised in terms of both a review of case notes and the narratives of individuals. All other domains were derived from the interviews with most responses derived from the questions around what participants did if they had a health problem/arranging use of health services. A favourable opinion of the study was given the institution of the lead investigator (CG) (details blind for review) and full details of our ethical protocol are available in the study final report [22].

RESULTS

Fifty-eight residents expressed an initial interest in taking part in the study; 39 had mental capacity and provided fully informed consent to participate in the notes review and 35 to the interviews as well. Interviews lasted for an average of 20 minutes (range 10 to 50) which reflected the frailty of the population who participated in the study. The interviews were undertaken by SLD, HM, HMa who were all experienced interviewers used to the challenges posed when conducting research interviews with care home residents. Our Public Involvement in Research team were actively involved in the recruitment of interview participants and were present during the interviews to provide support to the resident [23].

Complete records of service use were available for 31 residents. Residents are referred to by numbers representing the care home and their participant number (eg resident 11 would be care home 1, resident 1).

Characteristics of participants

The demographic profile of the 39 participants across the six care homes did not differ between case study sites and mirrored the typical care home population profile [24b] being predominantly female (90%) with a mean age of 86 (range 65 to 101 years) (table 1). The median length of residence in the home was 17 months (mean 25 months SD 28.46, range 1-132 months).

Accessing health care

The organisational context is important in understanding how participants accessed health care. Two care homes were each served by one general practice that provided weekly clinics in the homes; the other four homes were each visited by GPs from at least three different practices (two care homes worked with ten different practices each). All interview participants during the baseline interview reported that they were in contact with their GP and their narratives of service access were dominated by use of GP services. General practitioners and district nurses were the most frequently accessed services by residents. They were used by all participants during the 12-month observation period with a mean of 10 and 30 contacts respectively per resident per annum. However, there is considerable variety in mean GP contacts between care homes ranging from 4 to 16. (see Table 2). Although, on average, participants were in contact with, on average, 4 different health care services in the previous year (range 3-7) there were remarkably few comments in the interviews about other types of primary health care services such as community or specialist nurses, rehabilitation therapists, dentists, opticians or chiropodists or 'preventive' services such as flu immunisations.

Need for health care

Our data on the healthcare needs of participants was drawn from our documentary analysis of care home records. Residents had, on average, 4 different co-morbid diagnoses (range 1 to 11: mean and median= 4) and a median Barthel score of 15 (mean 14, SD 3.80), suggesting low levels of physical dependency.

Predisposing factors to seeking health care

Typically, in the Andersen and Newman model [21A,21B] predisposing factors focus upon the socio-demographic profile of individuals and how these frame decisions about accessing health care. The health beliefs, especially the attitudes and beliefs that individual's hold about their own health (and the potential of health services to mitigate or cure the problem) can influence perceptions of care needs and subsequent service use. Indeed these are the foundations of the health belief model and which has been linked to service use by older adults [32]. Our participants demonstrated high levels of morbidity and thus 'high' levels of health care needs (table 2). However, our interviewees gave a much more nuanced and age-related view of their health care needs. This revealed adjustment of their health care status in the light of their ageing body which inevitably influenced their decisions around health care access as demonstrated by narratives of expectations of what they should 'expect' from an ageing body and the ability of health care services to respond to these challenges-

I mean when you get to 81 you can't expect to be 16 can you really, you know what I mean? ... so I reckon all the tablets they've given me's kept me alive (resident 23 female aged 81)

Yes, but that's all, and that's the reason I'm here, it's not that I'm ill, it's to do with I can't walk.

What's the matter with your legs? What's the problem?

Old age (laughs).

You're wobbly on them, are you? Is your balance not very good or can you not... ?

I mean, 92...

Are you?

...what can you expect? (resident 41 female 92)

For some residents, their health care needs were translated into specific medical conditions for others an ageing body meant, having "good and bad days" rather than a specific health problems that meshed 'neatly' with the organisation and delivery of health care services.

You know, my health before, I used to go outside walking and still I'm going but I'm getting tired now, you know, and sometimes my legs is paining so when I went to the doctor yesterday, I said, Doctor ?, why my leg, he said, there's nothing wrong but that is you've got arthritis.

So does that mean you never feel unwell, or under the weather at all?

Yes, yes, more or less it, yes it's like that lovey. Not unwell, not ill, just some days are good and others less good. Some days I feel better than others but if I am no so good I have a quite day, that's all. It's not being ill, just a little bit dozy and quiet. And they leave me alone when I want to be and I like that. It's just one of those things. After all, I'm almost 94 now, and this body isn't as young as it used to be. (resident 23 female aged 81)

The notion that 'nothing could be done' for their health problems was commonly articulated.

I don't think I'm being funny, there's not much anybody can do for us, I know that myself, because I've had [??] my operations and I mean I've got an irregular heartbeat and take as many tablets. (resident 46, female aged 87)

Others did not feel they should 'bother' services with their 'problems or that there were others worse off than themselves or who had greater needs as these quotations illustrate.

That's right, yes, I was very... I get... when it was... when there's a lot of pain and it's there night and day and you do get tired of it but other people are the same so, you know, I mustn't grumble ... (resident 35, female 94)

How is your stoma now?

Horrible. But... (Pause) I try to manage but I mean, they look after us and the nurses are good with us because... Sometimes I think I'm a nuisance. (resident 46 female aged 87)

Do you ask to see the doctor?

No.

If you did ask what happens if you do ask to see the doctor?

Well I expect I would see him but I don't really want to bother them. (resident 44 female aged 81)

Well the trouble is you get to the point that are you bothering them unnecessarily.

Bothering who, the home or the doctor?

The doctor. I shouldn't say this really should I? But to me they're not, it's like there was a nurse, was a matron, she wasn't one of them was she, she was the boss person and here I feel they're all the same, all together. (resident 35, female aged 94)

I think the girls here try, but the GP is hopeless. ... (Senior) is usually right in what she says but the doctor seems to think we are all making a fuss about nothing.... (resident 63, male aged 84)

Personal expectations about their ageing body may combine with concerns about being a burden to care home staff, relatives or health care services, resulting in residents not expressing (fully) their needs, believing that they are to be expected in older age, that their needs are of a lower priority than other groups - or that it is inappropriate to complain about feeling unwell or to make demands on individual care workers by not 'bothering' them. In combination, these factors predispose participants not to seek care.

Enabling factors

Two key themes characterised our interview data in terms of enabling factors: the use of advocates or intermediaries to access general practice and residents' expectation of anticipatory referral by staff. Almost all interviewees, 31, described how they would tell someone at the care home if they felt unwell or thought needed to see a doctor. Typically, residents would talk to a trusted member of the care staff and expect that GP help would then be sought by the staff for them. Consequently, a range of staff within the home may be involved before the consultation is initiated as this quote indicates with the involvement of a key worker, manager and other staff before the GP is contacted;

I talk to my key worker first thing. Then going to the office, downstairs to the office, the manager, anybody, J or S, and he says, Mr P is worried about health, he's got... So he says, he think, need a doctor, they take appointment for the doctor, you know. (resident21, male aged 80)

(resident would discuss care need) with the main team, your key worker, or one of the care workers.....Or one of the home team, and we've got a manageress and I've got manageress, to them and then they get in touch with the doctor and they talk to the doctor and he knows whatever it is, and he will prescribe the tablets, but you mustn't go and buy tablets yourself because that's not right. (resident 23 female aged 81).

Three participants stated that they raised issues of their health with relatives, who would then inform staff to access the required services rather than going directly to the GP.

Well me daughter, as I say, she was a nurse years ago, she's very understanding and capable and she would know what to do... I know if I tell me daughter she'll pass it on (to the care home staff). (resident 31, female 80).

This use of intermediaries to seek care was not necessarily derived from a 'passive' acceptance of a dependent role but rather reflects the situation in which residents find themselves. However, this emphasis on the use of care home staff to facilitate GP access may also reflect expectations by residents of their role. One self-paying resident clearly articulated an active 'consumerist' approach by expressing that she was 'paying' for staff to do these things for her and that was what she expected.

I: *Do you ever want to arrange anything like this (GP referral) yourself?*

No, why should I be bothered with that. They are called care workers and so that's their job. Caring. That's what I pay them for and that's what I expect them to do. (resident 62 female aged 88).

Only one participant, resident 42, a 91-year-old female, directly initiated GP consultations as this extract indicates

I: *So if you needed to see a Doctor how would you go about it?*

R I'd go on a bus and see a Dr. XXX

I *So you'd take yourself off to see them?*

R I'd go myself.

I *So you wouldn't go through the staff here and ask them to make you an appointment?*

R Would I hell!

Linked to this was residents' expectation of anticipatory referral to GP services by the care staff. Half of our participants reported that care home staff knew them well enough to notice new health problems, identify changes in existing conditions and proactively seek GP help without the resident requesting this.

...they notice what I need and they arrange it for me when I need it, they are very good like that. Excellent I would say, they keep an eye on you and when they think you're bad they sort

it all out and they say that the Doctor or the Nurse is coming in and you just do that because they say to and it is all quite fine because they are the ones who know, aren't they? But as far as my health care I leave that up to them, they are the experts, aren't they? (resident 54, female aged 86).

Thus, residents had expectations that care home staff have a level expertise to both notice changes in their state of health and identify these changes as warranting medical attention. Some residents explicitly articulated their considerable confidence in the expertise of care home and health care staff, to the extent of placing all care decisions in their hands as they were 'the experts'.

DISCUSSION

Our study is novel in that it concentrated on residents' experiences of seeking health care access rather than professional perspectives and examined these experiences through the prism of the Andersen and Newman model [21A] of health care access using secondary analysis of qualitative interview data. It is important that the voices of residents are heard in terms of both service access but also living in care homes more generally [16]. The prior literature on service access for care home residents is dominated by professional, organisational and funding perspectives with the focus of research being upon how to 'make' services work together more effectively and/or interventions focused upon specific aspects of care such as end of life care [9] or reducing hospital admissions [25]. The experience of older people living in care homes as to how they access and experience primary health care services is noticeably absent. Furthermore, studies using the analytic framework of need, enabling and precipitating factors proposed by Andersen and Newman [21A,B] with qualitative data with older people and within the context of living in a care home are rare.

We completed 35 interviews with care home residents averaging 20 minutes in duration, which reflected the frailty of the study population. Gaining the views of residents is time consuming and resource intensive and inevitably our study is based upon data gathered from those who were well enough to participate and could provide informed consent. The focus of the interview was around residents' views on service access and how well services did (or did

not) work together. In this paper, we have reanalysed the data from the perspective of the Andersen model of health care access specifically looking for the narratives of residents around three key factors: their need for care, factors that enabled care access and precipitating factors. Although this is a 'secondary analysis' of our interview material the data link well with the three dimensions of the model as we had residents' responses to questions about what they do if they need health care and how they access such care.

Given the nature of the population it is not surprising that there are high levels of need for health care. This is evidenced by the multi-morbidity that characterised residents with most participants having 3-4 different diagnosed conditions. However, when we look at participants' narratives about their health care needs we see a more nuanced view of health in the concept of 'good and bad' days and coping with the vicissitudes of an ageing body. All participants had consulted their GP in the previous year and some were critical of the attitudes the GPs towards them feeling that they were not taken seriously or that their health problems were just down to 'old age'. This links with the negative factors that limited residents' predisposition to access health care which were highlighted by fatalistic comments that their problems were such that nothing could be done, that their problems were not that bad compared to those of other residents or that they did not want to 'make a fuss' or be 'a nuisance'. Thus, whilst participants experienced health problems these were not always translated into service use because these problems were 'downgraded' as just being due to their age or because of fears about being (over) demanding.

Our case study sites demonstrated variability in the mean number of GP contacts between care homes ranging from 4 to 16. As we have explored in this study such differences may reflect differences in need, although the average number of conditions per resident was broadly similar at 4-6. Another explanation for variability in GP access are the factors that enable or facilitate care access. In terms of factors that enabled health care access two key elements were identified: the role of advocates or intermediaries to arrange care, and residents' expectations that staff would monitor their health and proactively arrange services. Participants used advocates, predominantly care home staff, to access GP services, asking staff they knew to organise a GP consultation for them. However, the use of advocates to initiate care access does not necessarily imply lack of agency for residents in terms of

identifying their health care needs and seeking appropriate advice. Our results may simply reflect the care environment where residents lack the means of directly booking GP visits.

It is, however, important to contextualise the role of care home staff in arranging access to health care for residents in terms of the opportunities for staff and residents to discuss such matters. A study from Norway analysed recorded conversations between care/nursing staff and older people and observed the way that 'time limits' framed such conversations which were dominated by concerns about specific physical tasks and subject to interruptions [26]. This research also commented on the power imbalance between staff and residents, which may affect conversations about health needs and the limited opportunities for residents to talk about the things that were important to them. They also noted that lack of continuity of staffing limited the opportunities for older people to build relationships which, again, may limit the opportunities or confidence of care home residents to report on their health care needs.

Almost half of the residents interviewed said they expected care home staff to notice changes in their health and seek advice unprompted. The expectations held by participants that staff could monitor residents' health status, identify changes and proactively refer to services raises two key operational problems. First, the high turn-over of care home staff nationally, estimated at 20% (double the national average), may mean that staff do not know the residents well enough to do this [27]. This point about relationship building between staff and residents being compromised by staff turnover was noted in a study reporting staff-resident interaction in Sweden. Second, staff may (or may not) be able to identify key changes in the health status of residents and take the appropriate action. Hence, residents' expectations of care home staff in this respect may be unrealistic but may also reflect their own reticence in presenting their needs for care explicitly.

Anticipation by residents that care home staff will identify their health care needs and make appropriate requests for professional advice may reflect a range of factors. The nature of the health challenges faced by older people may be part of the answer especially reflecting concepts such as 'good' and 'bad' days rather than distinct and discrete illness episodes. Uncertainty about boundaries and thresholds for when symptoms such as pain warrant

intervention and are not just a manifestation of 'old age' may also influence help seeking behaviour by care home residents. For example, most community-dwelling older women with symptoms of incontinence do not declare them [28]. The same may be true of care home residents, but staff may be aware of their incontinence, able to gauge changes in symptoms and initiate appropriate referral. Age-related changes in cognition may influence help-seeking decisions, so that older individuals may be uncertain if they are interpreting symptoms or signs appropriately. The ability to integrate information and weigh up alternative explanations for symptoms or signs decreases with advancing age, as well as being associated with gender, ethnicity, socio-economic status and educational level. So, for example, a headache may be attributed to eye strain due to long periods of reading and not to adverse effects from new medication. Alternatively, these responses may reflect the trust residents have in the expertise and personalised knowledge of them held by care home staff. There is a clear need, if this expectation is shared more widely by the larger community of care home residents, to support the role of care home staff in terms of the day to day monitoring of the health of residents.

Residents presented the process of accessing general practice services as mostly unproblematic and straightforward. Their accounts suggested that all they did was tell the staff or the staff would know that a service was needed and arrange for this to be provided. However, accessing GP services from care home settings can be a complex process involving multiple actors (care home staff, residents, their family, the GP, and GP surgery staff), multiple decision points and referral processes within the home and within general practice [29] with decision making about care access limited to senior staff. Overt consumerism was not typical of participants. One self-funded participant clearly saw the role of care home staff in organising GP visits for her as an entitlement, because she 'was paying for it'. This account needs to be interpreted within the context that those who are self-funding are generally less frail than those who receive public funding for their care [32]. However, it does illustrate an 'active' engagement based around entitlement because of payment and raises an interesting area for further research investigating if the form of funding influences expectations about the limits of roles and responsibilities of care home staff.

Our study is novel in articulating the role given to care home staff by some residents, as an expert aware of the unspoken problems and able to initiate action about them. Care home staff, however, may or may not be able to accept of this role ascribed to them, or feel skilled enough to dispense it effectively. This paper highlights the importance to residents of representatives in accessing health care and argues that these people should be recognised and engaged when discussing care options. In this study these were predominantly staff but family members may also play this role. Turnover of staff in care homes may also hamper acquisition of knowledge about individual residents and limit their ability to identify key changes in resident health. Primary care practitioners may not always appreciate the role of care home staff as interpreters of residents' health care needs: GPs and other health care staff need to create opportunities for care home staff to share information and respect and utilise the information. The interpretative role of care home staff is constrained by how long the person has worked in the care home or whether this is a role they can assume. In contrast to support offered to care home staff around specific issues such as falls, there is little understanding or evidence about the best ways to equip and support care home staff to monitor residents' health on a day to day basis. More attention needs to be paid to this aspect of care home staff training and development [29b]. The INTERACT programme developed in the United States, focused upon developing clinical and educational tools to help staff identify changes in the health status of long term care residents [25]. As with other aspects of the NHS where different services interact, such as discharge from hospital, effective relationships built upon shared values and trust between professionals underpin effective provision of care [30]. From the GP perspective, there are significant challenges in working with care home residents because of the complex patterns of needs presented and some GPs are seeking to make provision of primary medical services to care home residents subject to different contractual arrangements [31].

Our study offers innovation in our focus upon a population rarely included in studies of primary care access or in studies evaluating the provision of care to residents. This is an important but neglected area of research because it is misplaced presumption that care home residents are already being 'cared for' Furthermore, we did not adopt perspective that focused upon enumerating the 'barriers' to GP access that is so characteristic of studies of

primary care and other service access. Rather we adopted a participant led approach whereby they described how they accessed services and framed this in the context of need, enabling and predisposing factors as proposed by Andersen and Newman [21A]. We saw clear evidence of enabling factors (using staff/family as intermediaries in care access) and predisposing factors which focused around 'normalising symptoms' or framing their needs in terms of the perceived inability of services to address these. Another approach to theorising accessing a GP is as a pathway. Ford et al identified a pathway that consisted of 7 stages (problem identification, decision to seek help, actively seeking help, arrange appointment, get to appointment, appointment and outcome)[11]. Within the care home context not all these stages may apply (getting to the appointment) or may be facilitated by others (making the appointment) and process is likely to be iterative rather than linear. These authors used a realist approach in their review which entails understanding the context (expectations of ageing, knowledge of the system for accessing care) and mechanisms (patient empowerment, health literacy, service provision model) of accessing a GP. Our study demonstrated the importance of context but, because it was a secondary analysis, could not explore each phase of the model or consider the mechanisms that were underpinning these stages. Future care home studies could adopt this model to understand how best to provide access to care for their residents and enhance this approach by including other important actors in the decision such as care home staff and relatives.

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References

- 1 CQC (2015) *The state of health care and adult social care in England 2014/15*
http://www.cqc.org.uk/sites/default/files/20151221_cqc_state_of_care_report_web_accessible.pdf
2. NHS England 2016 The framework for enhanced health in care homes
<https://www.england.nhs.uk/wp-content/uploads/2016/09/ehch-framework-v2.pdf>
3. British Geriatrics Society Failing the Frail, 2012.
http://www.bgs.org.uk/campaigns/Failing_the_frail_full_report.pdf
4. British Geriatrics Society quest for quality 2011.
http://www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf
- 5 and 6 Blind for review .
7. Blind for review
8. Gleeson LE, Jennings S, Gavin R, McConaghy D, Collins DR. Primary care in nursing homes revisited: survey of the experiences of primary care physicians. *Ir Med J.* 2014 107(8):234-6.
9. Goodman, C., Amador, S., Elmore, N., Machen, I., & Mathie, E. Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *Int J Nurs Stu*, 2013 50(12), 1639-1647
10. Goodman C, Dening T, Gordon AL, Davies SL, Meyer J, Martin FC, Gladman JR, Bowman C, Victor C, Handley M, Gage H. Effective health care for older people living and dying in care homes: a realist review. *BMC Health Services Research.* 2016 Jul 16;16(1):269.
11. Ford JA, Wong G, Jones AP, et al. Access to primary care for socioeconomically disadvantaged older people in rural areas: a realist review. *BMJ Open* 2016;6:e010652. doi:10.1136/bmjopen-2015- 010652

11b Elias T, Lowton K Do those over 80 years of age seek more or less medical help? A qualitative study of health and illness beliefs and behaviour of the oldest old. *Social Health Illn.* 2014; 36(7):970-85.

11c Veazie PJ How Older Persons Structure Information in the Decision to Seek Medical Care *Health Psychol Res.* 2014; 2(3): 1535

12. Evans G, Evans JG, Lasserson DS Questionnaire study of the association between patient numbers and regular visiting by general practitioners in care homes. *Age Ageing* 2012, 41: 269–272

13. Glendenning, C, Jacobs S , Alborz, A, Hann M A survey of access to medical services in nursing and residential homes in England. *Br J Gen Pract* 2002; 52:545–548

14. Shah SM, Carey IM, Harris T, et al. () Quality of chronic disease care for older people in care homes and the community in a primary care pay for performance system: retrospective study. *BMJ* 2011;342:912

15. Iliffe, S., Davies, S., Gordon, A., Schneider, J., Dening, T., Bowman, C., . . . Goodman, C. (2016). Provision of NHS generalist and specialist services to care homes in England: Review of surveys. *Primary Health Care Research & Development*, 17(2), 122-137. doi:10.1017/S1463423615000250

16. Andersen, Ronald M.; Davidson, Pamela L.; Baumeister, Sebastian E. "Improving Access to Care in: Chaning the U.S. Health Care System" (PDF). https://www.researchgate.net/publication/306017030_Andersen2014_Improving_Access_to_Care_in_Kominski_Changing_the_US_Health_Care_System. Jossey Bass. Retrieved 16 February 2015

17 Backhouse, T.; Kenkmann, A; Lane, A; Penhale, B; Poland, F and Killet A. Older care-home residents as collaborators or advisors in research: a systematic review. *Age Ageing* on line first January 2016.

18 Milte, R. et al Quality in residential care from the perspective of people living with dementia: The importance of personhood *Archives of Gerontology and Geriatrics* , 2016, 63 , 9 - 17 DOI: <http://dx.doi.org/10.1016/j.archger.2015.11.007>

18a Bradshaw, S. A., Playford, E. D., & Riazi, A Living well in care homes: a systematic review of qualitative studies. *Age Ageing*, 2012 41, 429–440

19. M. D. Rijnaard, J. van Hoof, B. M. Janssen, et al., "The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents," *Journal of Aging Research*, vol. 2016, Article ID 6143645, 16 pages, 2016. doi:10.1155/2016/6143645

20. Van Hoof, Verbeek, Felix, Wouters, Janssen, Eijkelenboom, Molony, Nieboer, Zwerts-Verhelst, and Sijstermans, "A three perspective study of the sense of home of nursing home residents: the views of residents, care professionals and relatives," *BMC Geriatrics*, vol. 16, no. 1, pp. 1–15, 2016

21. Condelius A, Andersson M. Exploring access to care among older people in the last phase of life using the behavioural model of health services use: a qualitative study from the perspective of the next of kin of older persons who had died in a nursing home. *BMC Geriatrics*. 2015;15:138. doi:10.1186/s12877-015-0126-9.

21A Andersen and Newman model Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Q Health Soc*. 1973;

21B Babitsch, Birgit & Gohl, Daniela & von Lengerke, Thomas. (2012). Re-Revisiting Andersen's Behavioral Model of Health Services Use: A Systematic Review of Studies from 1998-2011. *Psychosocial medicine*. 9. Doc11. 10.3205/psm000089.

22-24. Blind for review

24b Gordon, A. L., Franklin, M., Bradshaw, L., Logan, P., Elliott, R., & Gladman, J. R. (2014). Health status of UK care home residents: a cohort study. *Age Ageing*, 43(1), 97-103.

25. Ouslander, J. G., Lamb, G., Tappen, R., Herndon, L., Diaz, S., Roos, B. A., ... & Bonner, A. Interventions to reduce hospitalizations from nursing homes: evaluation of the INTERACT II collaborative quality improvement project. *Journal of the American Geriatrics Society*, 2011 59, 745-753.

26. Kristensen, D; Sundler, A, Eide, H Hafsjold, L; Ruddl Holmstrom I.

Characteristics of communication with older people in home care: a qualitative analysis of audio recordings of home care visits. *Journal of Clinical Nursing* 2017.

DOI: 10.1111/jocn.13807

27.

[Http://www.bournemouthcho.co.uk/news/14250553.Lack_of_funding_and_staff_shortages_the_storm_of_challenges_care_homes_face/](http://www.bournemouthcho.co.uk/news/14250553.Lack_of_funding_and_staff_shortages_the_storm_of_challenges_care_homes_face/)

28. Walters K, Iliffe S, Orrell M. An exploration of help-seeking behaviour in older people with unmet needs. *Fam Pract.* 2001; 18(3):277-82.

29 Orellana K, Manthorpe J, Moriarty J. (2016) What do we know about **care** home managers? Findings of a scoping review. *Health Soc Care Community*. Doi: 10.1111/hsc.12313.

29b. Close H, Hancock H, Mason JM, Murphy JJ, Fuat A, de Belder M, Hungin AP. "It's Somebody else's responsibility" - perceptions of general practitioners, heart failure nurses, care home staff, and residents towards heart failure diagnosis and management for older people in long-term care: a qualitative interview study. *BMC Geriatr.* 2013 13:69.

30 Shaw, J. Kontos, P., Martin, W., Victor, C. The institutional logic of integrated care: an ethnography of patient transitions ", *Journal of Health Organization and Management*, 2017, 11,1 82 - 95

31. 13 <https://www.theguardian.com/society/2016/feb/01/gps-urged-to-continue-visiting-patients-in-care-homes>

32. Baxter, Kate & Glendinning, Caroline. (2015). People who fund their own social care.

Baseline interview with residents-summary of topics covered

A. General health

How are you feeling today?

If you feel unwell/have a health problem what do you do?

B: Health Services

What health services do you use?

- How do you arrange that?
- What other health services come into the care home? (*Used or not?*)

What do you think of the health services you receive?

C: Integrated working

Do the health care staff work together with the care home staff?

Do you have enough involvement in your health care and any decisions that are made?

Table 1 Characteristics of the study population

	Care Home 1	Care Home 2	Care Home 3	Care home 4	Care home 5	Care home 6
Baseline characteristics	n=5	n=6	n=7	n=7	n=7	n=7
MALE	1 (20.0%)	1 (16.7%)	0 (0%)	2 (28.6%)	2 (40.0%)	0 (0%)
Mean age (years)	90	84	89	84	84	84
Length of residence (mean months)	30	30	20	11	41	25
Mean number of conditions*	6	6	2	3	6	5
Mean number of medications**	13	6	11	9	6	11
Mean Barthel score ***	11	16	15	13	14	15
Service use	n=3	n=5	n=7	n=5	n=6	n=5
Mean (SD) GP contacts over 12 months	10.7 (8.6)	4.2 (3.0)	8.0 (6.3)	16.4 (6.8)	3.8 (3.2)	9.8 (7.0)
Mean (SD) district nurse contacts over 12 months	30.0 (45.9)	5.4 (9.2)	13.8 (28.0)	1.3 (0.9)	6.3 (7.1)	67.9 (144.7)
Mean (SD) number of services used in 12 months	6.0 (0)	3.4 (0.89)	4.1 (0.69)	4.4 (1.5)	3.2 (1.2)	4.0 (1.2)

*difference between homes significant at 0.002; * difference between care homes significant at 0.005 *** Barthel score range 0 (totally dependent) to 20 (totally independent)