Attitudes, perceptions and behaviours associated with Hospital Admission Avoidance in the Frail and Elderly (HAAFE study)

A Report to Northumberland Clinical Commissioning Group

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Contents

Summary

21 participants took part in this study, of which 13 patients had no unplanned hospital admissions in the twelve months prior to their interview. Out of the remaining participants two participants had one, one participant had three, two participants had five, one participant had eight and two participants had twelve unplanned hospital admission in the 12 months prior to their interview. Five of the eight participants that had been to hospital as an unplanned admission prior to the interview lived alone and generally had higher rates of hospital admission than those from this subgroup of patients that did not live alone.

Generally participants in this study perceived that they had reasonably good health, although felt that they had a lack of control over their wellbeing, and that old age had a detrimental effect on their health. Some participants, however, perceived that they were a burden to the healthcare system, and some participants recounted that they often felt anxious about their health with those that lived alone explaining that they felt the most vulnerable. Participants perceived that taking preventative medication, having physical aids such as a walking frame or personal alarm if they fall, physical adaptations within their homes such as adapted shower or stair lift, living a healthy lifestyle that included healthy food and exercise, resting and knowing their limitations were enablers of avoiding an unplanned hospital admission. The coping mechanisms described by participants to help them manage their health included positive thinking, mental disengagement such as doing an activity to take their mind of their health, focus and venting of emotions, and acceptance of the effects of old age and/or their health condition, or accepting that they can no longer do certain things anymore.

The majority of participants described a social support network of family, friends and/or neighbours that contribute to helping them manage their health by both emotional and physical support mechanisms. However, for a number of participants, their spouse had become their carer, and participants were conscious that this was a strain on their spouse. Six participants that took part in this study had paid carers, and the level of care required varied from a daily visits in the morning, more frequent visits of 2-3 times a day, to 11 hours of care each day. Participants that had carers generally accepted they needed care and felt the care they received was good and continuity in care from carers was preferred.

Participant perspectives on access to GP appointments were mixed, with some recounting they usually don't wait more than 2 days; while dissatisfaction was seen amongst participants who commented that they sometimes have to wait up to two to three weeks. Nearly all of the participants were unaware of what the Northumberland High Risk Patient Programme (NHRPP) was or why they were registered on it. All participants explained that they enjoy being in their own homes, but accepted that they would have to go into hospital if they needed care. There were mixed views on the hospitals within the North East of England, including lack of decision making by hospital doctors, long waiting times, the temperature being too cold, and the hospital being too busy to cope. However, generally participants were very positive about the NHS, although some participants recounted experiences where they felt the health care system was inadequate including GP surgeries being more focussed on cost saving than providing good health care, communication issues between GP surgery and hospitals, lost medical records, incorrect medication dosages, and lack of staff and staff time.

Continuity of care was described by participants and generally participants saw the same GP when they could, and described that this contributed to the GP having a good knowledge of

their health, and allowed for trust, confidence and a relationship to develop. Most participants described having routine check-ups with a number of health professionals, such as nurses and consultants, and recounted having confidence in these health professionals and largely felt that the health care they receive was excellent. Continuity of care, however, was affected by high demand for a particular GP, high turnover of staff and GPs being absent. Lack of confidence in the GP, lack of continuity of care from the GP, and/or the absence of support from family, friends or neighbours were described by participants who had at least one hospital visit in the 12 months prior to the interview. Moreover, the majority of these patients lived alone, felt the most anxious and vulnerable about their health, and were most likely to seek reassurance for their health and have an unplanned hospital admission.

Finally, patient decision making was described by some participants including stopping taking prescribed medication, and deciding against going for an operation or into respite care. However, some participants felt that there was more shared decision making between the patient and health professional than there had been previously.

Key points: implications for hospital admission avoidance

- Participants perceived that taking preventative medication, having daily living aids, physical adaptations within their homes, living a healthy lifestyle and resting were enablers of avoiding an unplanned hospital admission. Highlighting the importance of these *physical enablers* to patients, carers and healthcare providers will contribute to helping high risk patients avoid an unplanned hospital admission.

- Reinforcing the *coping strategies* that high risk patients use in their approach to the management of their health, including acceptance of the effects of their health condition and/or old age, acceptance of not being able to do certain things anymore, positive reinterpretation and growth, mental disengagement, and focus and venting of emotions could be a simple beneficial solution that could help patients cope with their health, and has the potential to reduce the perceived vulnerability and anxiety that a patient feels, and in turn reduce unplanned hospital admissions.

- Emphasising the importance of patient *support networks* from family and friends, especially in the high risk patients that described being most anxious about their health, would be advantageous. However, for those with spouses, the strain on the spouse from the physical and mental demands and responsibility of being a carer should be considered.

- Promoting the *continuity of care* from the GP and other professionals, and the perceived consistency of care amongst GPs, will contribute to improving the trust and confidence that a high risk patient has in their GP, help encourage patient outcomes and wellbeing, and thus could help reduce unplanned hospital admissions. However, this may be challenged by patient decision making.

Aims and Objectives

Research question: What are the enablers and barriers of staying at home and avoiding hospital for patients considered of being at high risk of hospital admission?

Aims:

To explore the experience of patients who are registered on the Northumberland High Risk Patient Programme (NHRPP).

To explore demographic, health, care management and behavioural factors that may contribute to enabling high risk patients to stay at home and avoid being admitted to hospital.

Objectives:

To perform an in-depth interview study with patients registered on the NHRPP to characterise management and behavioural barriers and enablers to staying at home.

Background

Since 1974 the UK population aged 65 and over and 75 and over has increased by 47% and 89% respectively, and these age groups now make up close to 18% and 8% of the total UK population (ONS, June 2015). In 2013 life expectancy at 65 was reported to be 21 years for women and 19 years for men (ONS, 2013), and the total UK population is expected to increase by 3% between 2015 and 2020, with the population aged over 65 predicted to increase by 12%, the population aged over 85 by 18%; and the population aged 100 years and older by 40%, giving an increase in 1.1 million, 300,000 and 7,000 people in each age group respectively (Parliament, 2015)

Frail older people have been described by the Department of Health (DH) as being vulnerable as a result of health problems such as stroke or dementia, social care needs or a combination of both (DH, 2001). Currently in the UK one in ten people aged 65 and over, and one in four aged 85 and over is described as frail. Falls are one of the factors associated with hospital admission in the frail and elderly with the rate of falls increasing with age, and amongst the population aged 85-89 years nearly 25% of men and a 33% of women had a fall in the last five years. Dementia is also associated with increasing age and 4% of the UK population aged 75 to 79 are reported to have dementia; while a higher prevalence of 25% is seen in women and 20% of men aged 95 to 99 (Mortimer and Green, 2015)

Since health generally decreases with age, costs to adult social care, community-based health services, outpatient appointments, non-elective admissions and elective admissions all increase with age, with those aged 75 and over having the greatest cost to health and care services, being close to 28%, 46% and 89% higher than people aged 65-74, 55-64 and 45-54 years of age respectively (Oliver et al., 2014). With an increasingly elderly population with complex co-morbidities, disability, frailty and high social requirements people over 65 account for 51% of gross local authority spending on adult social care (HSCIC, 2013) and care of people with long term conditions accounts for 70% of the money spent on health and social care in England (DH, 2015).

Health care systems are currently under severe pressure to optimise care while keeping costs down and this is not just a problem in the UK. Previous studies based in the United States have investigated methods to reduce the pressure on hospitals. In a randomised trial of hospitalised patients aged 65 and over (N=1388), patients that received care during inpatient geriatric units had significant improvements in the scores of their SF-36 health survey, daily life, and physical performance compared to those who received usual inpatient care, and at one year patients from the outpatient geriatric clinics had better scores on the SF-36 health survey than those from the usual outpatient care. However, costs at one year were similar for both groups and intervention during inpatient stay and extension of follow up after discharge did not reduce hospital admissions compared with usual care (Cohen et al., 2002). Additionally, in a different trial of high risk low income patients aged 65 and over (N=951) a community multidisciplinary team of GPs, geriatricians, community nurses, pharmacists, physiotherapists and social workers was created to relieve pressure on secondary care resources. Despite involving detailed assessments and management plans tailored to individual patients, weekly meetings, monthly patient contact, and annual review of procedures by the whole team, the trial had no impact on admissions to secondary care compared with usual care (Counsell et al., 2007). Moreover, in an qualitative study by Duncan et al. (2016) specialist geriatric input into primary care multidisciplinary team meetings was felt to have little impact on reducing hospitalisation.

In another randomised trial consisting of people aged 65 and over (N=792) patients were screened for target geriatric conditions including cognitive and functional impairment, depression, falls and urinary incontinence. Following this a combination of structured telephone assessment, referrals and recommendations to specialist services such as geriatric medicine and psychiatry, audiology, urology, rehabilitation and social services, with continuing telephone case management were used to target this cohort and investigate whether a system of screening, assessment, referral, and follow up provided within primary care improved the healthcare outcomes for high risk older outpatients. Although the intervention increased recognition and assessment of target geriatric conditions, hospital admissions were not lessened and no reduction in admissions compared with the usual care group was found over a three year follow up (Rubenstein et al., 2007).

There is a growing need to develop ways to improve management of the high risk patients and relieve pressure within the health care system. Identification of patients as ‘high risk’ of admission to hospital due to frailty with enhanced care planning within primary care is the current consensus with the aim to improve patient care and reduce unplanned hospital admission. In the UK the Northumberland High Risk Patient Programme (NHRPP) was developed to incorporate the Frail Elderly Pathway and the Integrated Care COPD programmes, and was introduced as a combined health and social care platform. The NHRPP includes people with long term conditions and/or those at high risk of hospital admission or readmission, and aims to deliver continuity, reduced duplication and deliver patient-centred care (NHS, 2013). The programme has been running for three years and an evaluation of the NHRPP by Duncan et al., (2016) showed that patients felt that they had excellent same day service when contacting their GP surgery, and also felt reassured after receiving follow up calls after hospital discharge, however, patient knowledge of the NHRPP was lacking, and generally so was any care planning. Why certain high risk patients are able to stay at home and avoid hospital admission or readmission is currently unknown, and all interventions trialed to date have failed to reduce hospital admissions.

Why is this important?

Factors that may explain why some patients are able to stay at home may include knowledge/ information accessed by the patient, effective care planning, access to health professionals, follow up calls after discharge from hospital, self-management and individual health beliefs (Duncan et al., 2016), as well as other unexplored behavioural factors. Patient ability to recover after functional decline (Felten and Hall, 2001, Felten, 2000), age discrimination, medicine management, strokes, falls, mental health, healthy lifestyle promotion, level of care qualification of carer, self-efficacy, respect and dignity during treatment, control of painful and distressing symptoms, social care, spiritual care, complimentary therapies and bereavement support may also have an influence on the health status of a frail and elderly patient (DH, 2001). The strength of any of these factors contributing to admission/readmission is currently unknown. Further investigation is required to recognise the interaction of physical, mental, health and social factors which can improve independence and quality of life helping frail and elderly patients to stay at home and avoid hospitalisation.

There is currently no published evidence to characterise those high risk patients that do manage to stay at home and avoid unplanned hospital admissions. Identifying the enablers of staying at home can be used to improve the management of high risk patients and increase the population of patients that are able to stay at home and avoid hospital admissions, reducing healthcare resource implications and costs, as well as improving the wellbeing and quality of life of this cohort of patients.

Method

Study design

This was a qualitative study that used in-depth interviews with patients to explore the experiences, attitudes and perceptions of high risk patients to their health and the health care they receive, and explore the behavioural factors that contribute to the avoidance of unplanned hospital admissions.

Approvals

05.08.2016 - Ethical approval was obtained from North West - Haydock Research Ethics Committee. The committee requested that patients that lack capacity should not be included in this research

08.08.2016 - Ethical approval was obtained from University of Sunderland Ethical Committe.

05.09.2016 - Governance approval was obtained from the Health Research Authority (HRA)

27.09.2016 - Statement of activities approved

Recruitment and Participants

GP surgeries were identified through Northumberland CCG and all 44 surgeries registered on the NHRPP were asked to be involved in the study. 15 surgeries agreed to take part, and 21 patients were recruited from seven GP surgeries.

21 participants were interviewed, of which 13 patients had no unplanned hospital admissions in the twelve months prior to their interview. Out of the remaining participants two participants had one unplanned hospital admissions during the twelve months prior to the interview, while one participant had three, two participants had five, one participant had eight and two participants had twelve unplanned hospital admission in the 12 months prior to their interview. Twelve participants were interviewed alone, however, the spouse of the participant was also present for seven interviews, while the granddaughter or the carer was present for two participant interviews. Five of the eight participants that had been to hospital as an unplanned admission prior to the interview lived alone and generally had higher rates of hospital admission than those from this subgroup of patients that did not live alone. Participant characteristics are shown in Table 1.

Table 1 Participant Characteristics

Patient ID	Gender	Age	Number of hospital visits in 12 months prior to interview	Interviewed alone	Live alone	Carers	Co-morbidities
Patient-1	Female	71	0	No – Husband present and contributed	No	No	Hypothyroidism, type 2 diabetes, previous breast cancer, depression, vitreous detachment in both eyes, hypertension
Patient-2	Male	90	0	Yes	No	No	COPD, atrial fibrillation
Patient-3	Male	73	3	Yes	Yes	Yes	History of strokes, Parkinson's Disease
Patient-4	Female	76	0	Yes	No	No	Osteoporosis, vertebral wedge fractures, coronary stent, leaky heart valve, kidney problem
Patient-5	Female	91	0	Yes	Yes	No	Type 2 diabetes, atrial fibrillation, hypothyroidism
Patient-6	Male	96	12	No – Granddaughter present and contributed	Yes	Yes	Unstable angina, history of multiple pulmonary embolisms, enlarged prostate, haemorrhoids, diverticulitis, asthma, osteoarthritis, poor eyesight (after cataract procedure), chronic kidney disease stage 3, ischemic heart disease, postural hypotension, benign paroxysmal vertigo
Patient-7	Male	78	0	No – Wife present and contributed	No	No	Type 2 diabetes, gout, arthritis, sleep apnoea
Patient-8	Male	89	0	No – Wife present and contributed	No	No	Venous leg ulcers, hypothyroidism, high cholesterol
Patient-9	Male	89	1	Yes	No	No	Angina, stroke, prone to falls, arthritis
Patient-10	Male	64	0	No – Carer present and contributed	Yes	Yes	Fibrodysplasia ossificans progressiva (FOP), osteoporosis, IBS, hypothyroidism
Patient-11	Female	87	0	Yes	Yes	No	COPD

Patient-12	Female	58	0	Yes	No	No	Breast cancer
Patient-13	Male	85	0	No – Wife present and contributed	No	Yes	Prostate cancer, atrial fibrillation
Patient-14	Female	63	0	Yes	No	No	COPD, hypothyroidism
Patient-15	Female	75	5	Yes	No	No	COPD
Patient-16	Male	78	0	No – Wife present and contributed	No	No	Ulcerative colitis, COPD, tremors, high cholesterol
Patient-17	Male	80	0	No - Wife present and contributed	No	No	Bronchiectasis, heart condition,
Patient-18	Male	79	12	Yes	Yes	Yes	Bowel cancer, kidney failure, heart condition, COPD
Patient-19	Male	79	1	Yes	Yes	Yes	Heart condition, stroke
Patient-20	Female	80	8	Yes	Yes	No	Recovering from pneumonia, stroke, breathlessness
Patient-21	Female	58	5	No – Husband present and contributed	No	No	Asthma, reflux, sleep apnoea, heart problems, prone to anaphylaxis, prone to hyperventilation

Data collection and analysis:

The interviews were conducted by Dr Rosie Dew (RD) working with Professor Scott Wilkes (SW) using an adapted grounded theory methodology. Box 1 shows the final interview topic guide used to guide the semi-structured interviews. Interview data were coded and then analysed using constant comparison of the data, and interview and data analysis proceeded in series. As the interviews progressed, themes emerging from the data informed questioning in the subsequent interviews (Denzin and Lincoln, 1994). Interviews were audio-recorded, fully transcribed and fully anonymised. Data analysis was conducted by RD and SW, and data were categorised into emerging themes negotiated between RD and SW. Figure 2 shows a concept diagram of the themes that emerged from the data.

Box 1. Topic Guide for Interviews

How would you describe your health?
What do you think about the health care you receive?

Do you have a care plan?
Can you tell me about your care plan?
What do you think about your care plan?
What do you think about your carer/s?
Do you always see the same carers/?
How would describe your relationship?

What do you think about the healthcare you receive?
What do you think about your access to your GP
How often do you see your GP?
Do you have a preference for a particular GP?
What do you think about your GP?

Do you see a nurse? Same nurse?
Do you see any other health care professionals?
How would you describe your relationship with your nurse/GP/other health care professionals?

Do you feel there is shared decision making regarding your care? Patient/ family decision making
How satisfied are you with the health care you receive?

Do you know what the High risk patient programme is? Why you're registered?

When was the last time you had an unplanned admission to hospital?
Can you tell me about it?
Why do you think you have not been into hospital recently?
What do you do when you're not feeling well? Do you call GP/999?
How would you describe your attitude towards your health?
How does it make you feel when you are not well?

How would describe your approach to your health?
Do you feel you are dealing with your health in the correct way?

How do you find going into hospital?
Can you describe the last time you were in hospital?
Did anything different happen to what your GP could provide?
How do you find staying at home?

How would you describe your attitude to your health?
How do you cope with your health conditions?
Does continuity of care affect your ability to cope?
Do you feel you are dealing with your health in the correct way?

Could you describe your support network or social contact?
Who does the cleaning/ cooking/ shopping/ washing/ bathing?

What are the enablers of staying away from hospital?
What are the barriers of staying away from hospital?

Is there anything else that you think may stop you from having repeat hospital visits?

Is there anything else you would like to discuss?

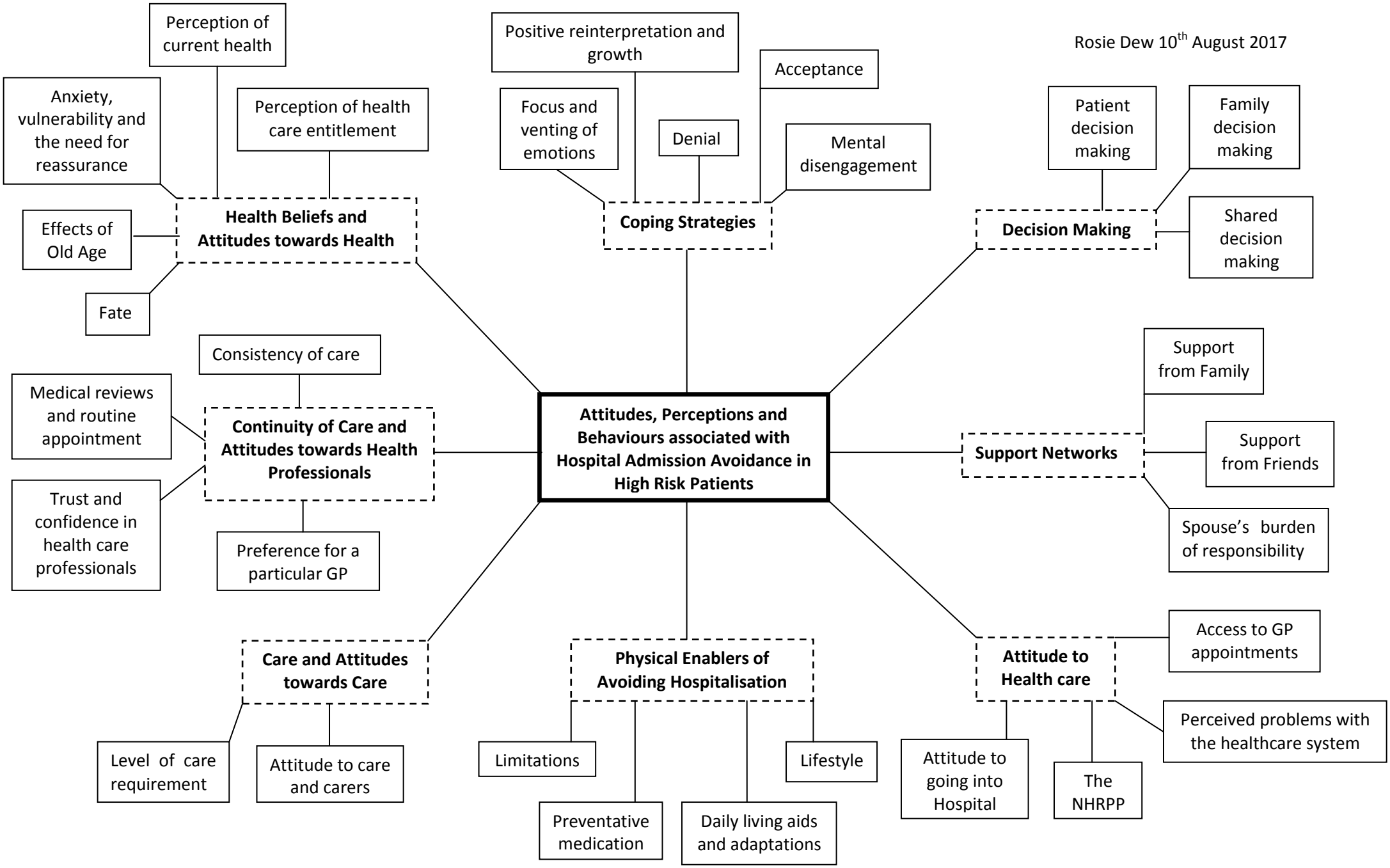

Figure 2 Concept diagram showing the themes that emerged from the interviews

Findings

1. Health Beliefs and Attitudes to Health

Perception of Current Health

The majority of participants recounted that they felt their health was reasonably good, however, participants commonly mentioned their conditions as a negative factor on their wellbeing, although acknowledged that they are controlled by medication and help from carers:

> *Reasonable for my age. Yeah. Nothing that's sort of going to, sort of, kill me in the near future, I don't think. I mean, I realise I've got a lot of conditions but they're all being controlled. Admirably, by the NHS. Keeping me going. With all my pills and potions. (Patient-1, female, 71 years old)*

> *Well… Maybe 70% out of 100 [score for health]. I'm fairly good, if it wasn't for the Parkinson's. (Patient-3, male, 73 years old, 3 x hospital visit prior to interview)*

> *That's a difficult one because I say I'm alright, but I know I'm not alright because the atrial fibrillation and the… Well, the diabetes – that's controlled. That's alright. That's been controlled for a very long time. And I think if the atrial fibrillation… And old age – it's a combination. So the health is okay, but I mean… I get by. (Patient-5, female, 91 years old)*

> *Well, I think my health is pretty good, but I'm disabled, of course. I feel... I feel alright. I'm grand. (Patient-7, male, 78 years old)*

> *Hah! It's difficult because I feel very well. And... I'm not sure how I can describe it further. On my present medication with my present system of carers, I feel fine. (Patient-13, male, 85 years old)*

However, some participants felt their health was variable or poor, with some participants recounting that they have good days and bad days, or that their health declines throughout the day:

> *At the moment, up and down. Because of the crushed vertebrae. I've got to be very careful not to crush the other one. Because the osteoporosis doesn't help, you know. Up until about June of this year, I would have said marvellous. Marvellous. But then I did [my back]. So it's really up and down. (Patient-4, female, 76 years old)*

> *Well, I'm saying poorly. Now, I'm great, right. And as the day goes on, I go downhill. In the morning, I hate getting up. I hate getting up in the morning, because I can get the first two hours over - that's great. Then I... And then I go down on the day, like... (Patient-15, female, 75 years old, 5 x hospital prior to hospital)*

> *My own body functions. My own stats are very good. But I am very bothered and weakened by the lack of breath and the breathing difficulties that I have. And I have good days and bad days with that. Sometimes and I'm fine and I can go out and potter about, other days I can't move from the chair. And I'm gasping and my legs are very weak and I'm poorly. And yesterday, I had a bad day yesterday. And I'm a*

bit better today. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)

Sometimes I'm champion and other times I'm not. You see, I've got a bad heart. I've got bad kidneys. (Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

There were mixed views from participants regarding whether they felt they were approaching their health in the correct way. Some participants, such as Pateint-15 below, felt that keeping their health condition under control by medication or following their GP's advice meant they were dealing with their health correctly, while Patient-20 hoped she was approaching her health correctly but felt unsure as she felt she had not had any guidance. Moreover, Patient-12 commented that it was important to feel in control of her health by looking after her physical health the best way she can:

Because [Doctor] has told me what to do. So I'm doing exactly what he says, so I'm doing the right thing. (Patient-15, female years old, 75, 5 x hospital visits prior to interview)

I hope I am. I can only think... You know, I can only hope that I am. But I've got no guidance, have I? No guidelines. I'm just doing the best I can on a daily basis. So we'd hope for the best. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)

I'm not sure that I've ever thought about it in terms of being correct. I think I… I hope… I assume that what I'm doing is along the right lines. But I don't make time to check this out, really. Or look for occasions to do so. (Patient-8, male, 89 years old)

I don't know whether that's the right approach or the wrong approach, but you just have to do what I think… I think it… Because I… It's very important, I think, that you feel in control of the situation. And as long as I feel as if I'm contributing as much as I can towards my physical health, then hopefully the drugs will do the rest. You know, that's kind of how I feel. (Patient-12, female, 58 years old)

Fate

A number of patients felt that, aside from good medication adherence and living a healthy lifestyle, they had a lack of control over their health, and perceived that fate was a reason for becoming unwell and needing to go to hospital:

No, because I think… I mean, no-one can help if they have something that strikes them down and they need hospitalisation. But… At the moment, I feel I'm on an even keel and obviously I haven't needed an admission. But, I mean, no-one can foretell. I don't… I don't look upon it as me keeping myself out of hospital. I just think it's… Fate and life and… Nothing has gone sufficiently wrong yet. (Patient-1 female, 71 years old)

Because I might fall over and break something. You never know. You don't know what's going to happen tomorrow, you know. Like the time I got pneumonia. The first thing I knew about it was I was sitting here one Sunday afternoon and I just slid off the chair down to there and couldn't get up. And I felt alright. I couldn't move. So one or two of the lads came around and picked me up and... I sort of waddled

round - I went into the bathroom, collapsed over the toilet and smashed it. And how long was I there? Four or five hours? (Patient-7, male, 78 years old)

If it's going to happen, it's going to happen. Whatever is going to happen, is going to happen, you know. That's it. Aye. (*Patient-15, female, 75 years old, 5 x hospital visits prior to interview)*

Moreover, Patient-21 felt she had very little control over her health and that her hyperventilation attacks can occur very quickly without much warning:

I've had massive amounts of attacks. Since… Since then. Collapsing. I don't know what and why. I've really never got down to… Hyper… Like, sort of, hyperventilation. And not being able to breathe properly. It comes on so quick. I can't stop it. You know, I can be lying here asleep – doze off, wake up, I'm straight into it. It doesn't… I can't stop it (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)

Effects of Old Age on Health

Almost half of the participants mentioned the negative effects of old age on their health, either contributing to their health conditions, contributing to medication complications, or effecting deterioration of bodily functions such as iron absorption, eyesight, getting tired quicker and not being able to do things they used to be able to do:

I have chest problems, and I have heart problems. And I have knee problems. I'm a problem. It's arthritis in the knee. It's old age. (Patient-2, Male, 90 years old)

We were in West Wales, and I... I collapsed. And I was out for quite some time. And people rang 999, didn't they? And I was taken to Havefordwest. And eventually they decided that it was a drug I was taking, which was called citalopram, which is an antidepressant. That it had lowered my pulse rate. And that was age-related. It did say... It did say on the side effects. But anyway, I had collapsed and I had been out quite a while. (Patient-1, female, 71 years old)

Aye. More like a car engine – it begins to deteriorate as you get older, don't you think? (Patient-3, male, 73 years old, 3 x hospital visits prior to interview)

I was getting quite puffed yesterday – but then again you just say, well, that's being old. You get puffed. And I would say to people, "I don't walk as well now. I don't walk as well now." I go in the car to get to places. But I still walk along to the garage. I walk along on that front. So… That's the situation. (Patient-5, female, 91)

So I have iron problems, which you get with old age because you don't absorb the iron they're treating. And… Numbness in your feet. You can't feel. And things like walking on sponge or you constantly get cramp and… You have to get… Your eyes aren't marvellous, and you get those seen to because you want to still drive. Now it's nothing but everything is deteriorating. (Patient-11, female, 87 years old)

It's hard as you get older. You see, as you get older… Parts of your body, which you rely on all… They start to deteriorate. Your eyes go. I just use them for reading, like. (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)

Perception of Health Care Entitlement

A number of participants felt that they were a burden to the NHS and described instances where they felt they were a 'bother' to the GP. Additionally, Patient-5 described circumstances where she had decided against seeing the GP, while Patient-4 recounted actively going against the advice of her GP, purposefully avoided going into hospital and instead managed her pain at home with pain killers, both being examples of self-management:

Because... I don't know, I just... I'll not bother them today. You know, I'll not bother the doctors today. (Patient-15, female, 75 years old, 5 x hospital visits prior to interview)

If you need them [GP] - fair enough - it's there. You try not to... Bother them if you're not... (Patient-7, male, 78 years old)

Earlier this year I had a very difficult time, I couldn't understand at all why I felt not well, really. I didn't want to do anything. And I just put up with it because… Two things – one, you think, well, it's old age anyway. And the other is, oh, you can't be bothering the doctor again. And I put up with it. (Patient-5, female, 91 years old)

I don't see the point because I have been taken in to hospital overnight and it's taking up a bed. And I could be at home. And I know I could be at home. So therefore I would have to be… I know Doctor [Name] keeps saying it's not very sensible. Because when you get a pain – if you have a heart pain or anything… But if I rest and if I take the spray for that and rest, then it's okay. I take pain killers. All of this and rest, you know. (Patient-4 female, 76 years old)

Moreover, a few participants felt they did not want to occupy a bed in hospital as they felt these should be available for other people who are more unwell:

"They'll keep you in." I keep thinking there's always somebody worse off. Needing the bed more. (Patient-14, female, 63 years old)

I just sometimes think that, you know, I'm sure there's more you're to be treated for here, rather than having to take up a hospital bed. I have, you know… Hospital beds should be for those people who really, really need them. (Patient-12, female, 58 years old)

Conversely, patient-18 perceived that having to wait until the afternoon to see the GP after calling for an appointment in the morning was unsatisfactory and often resulted in him reluctantly calling 999. Moreover, he also felt that it took too long for the nurse to come to see him, with him having to wait up to three hours:

And you phone at half past eight in the morning, and you can't see him until half past one in the afternoon. Which I think is wrong. And he said, "If you need

anything – phone 999." Well, 999 is getting sick of this, you know? Phoning and phoning and phoning. And the doctor is coming out and telling me if you need an ambulance or not. Surely. And I tried to make that point to them, but it's a waste of my time, talking…….. And I've got to phone 999 for this. But they ring all the nurses, and it takes the nurses three hours to come out. (Patient-18, male, 79 years old, 12x hospital visits prior to interview)

Anxiety, Perceived Vulnerability and the Need for Reassurance

Close to a quarter of patients reported feeling anxious about their health, and becoming frightened and stressed, such as when unfamiliar symptoms arise. Moreover, Patient-5 and Patient-20 recounted that living alone contributed to the anxiety they felt about unexpected and unknown symptoms:

Sometimes I get very frightened with my health, you know. (Patient-4, female, 76 years old)

My attitude towards my health is rather mixed, because I am a bit anxious at times. When... When I have feelings and pains that I don't understand. I think it's if you know what's happening, then you can cope. But when you get sudden twinges and you go, oh, what was that? And you know that there's nobody there to ask, then you worry. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)

I suppose whether you're on your own or you're not on your own, you get anxious when things aren't just exactly as you think they ought to be. And just to have somebody saying, "There, there – you're alright." And just sit quietly or… (Patient-5, female, 91 years old)

In the case of Patient-18 who lived alone, was partially sighted and hard of hearing, anxiety was a prevalent topic mentioned during his interview, and he was fearful of his relevant heart complications, knocking his cannula in his arm and bleeding to death at night, and struggling to breathe at night, and this had contributed to 12 unplanned hospital admission in the 12 months prior to his interview. Moreover, both Patient-18 and the husband of Patient-21 mentioned the negative effects of stress on wellbeing:

Well, you can bleed to death, you know. And you're frightened to go to sleep, you know. And you see the blood coming through. Well, you've got to phone them [nurses]. I mean, they put thick bandages on. There must be a lot of blood there to come through those bandages. Because you can see the blood in, you know. And I get worried and I can't sleep. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

No, I don't know, darling. I don't know. I try to stop them [repeat hospital visits] if I can myself. They stopped phoning 999, you know, but… I get stressed and… Anxious. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

The problem is, is that's because she's thinking… Over-thinking all the time about what we do and where we go. And how we plan things. Is that it works out in stress. And the grandkids, my daughter, she works… They work her up. She gets herself worked up, and that can bring an attack on as well, with the stress. Husband of (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)

Some participants described that they felt vulnerable regarding their health and frailty in terms of falling down and not being able to get back up again, during the early stages of cancer or because their health had deteriorated:

> *Not really, because I'm… In the dark moments, yes, you realise how vulnerable you are. (Patient-5, female, 91 years old)*

> *If I fall over and I get flat on the ground, I can't get up. You know. (Patient-7, male, 78 years old)*

> *I know them all so it doesn't really… It doesn't really matter so much. But in the early stages, yes, continuity is very important. Because you're very… You are very vulnerable. (Patient-12, female, 58 years old)*

> *I felt more… Vulnerable is too strong a word. But I've felt vulnerable, more so, in the last two to four years. And I think that's just down to not being able to rise from a chair. As quick as I used to. (Patient-16, male, 78 years old)*

> *I mean, I am old. The body starts to shut down, really. You've got to think that as well, and put that into consideration when you're not feeling very well. And think, you know, you're old. Give yourself time, calm down. But it's a bit worrying when you can't breathe and you live on your own, you know. There are people who would come. But, I mean, they can't do anything except sit there and hold my hand and make some tea. You know? (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

A few participants described scenarios where they would seek reassurance for their health such as ringing the GP surgery for advice or from follow up calls. Additionally, Patient-20 described that she had requested that she would like to have regular health checks for reassurance, however, this was not granted:

> *We had a letter from the surgery not long ago, explaining the various ways we could get in touch and… I mean, I knew that I could ring and ask for them to ring back. And that was one of the ways they said……Being able to phone and get some… It's not so much… It may be advice, but in some ways it's reassurance. (Patient-5, female, 91 years old)*

> *Well, I mean, it puts your mind at rest if you have a follow-up call and everything is still alright and… So you just, you know… It's okay. (Pateint-4, female, 76)*

> *And so the form that I fill... The form in - that came. Was I having this, was there anything I wanted? And I put down I would like regular medical contact with some sort of a practitioner. A district nurse, you know. A care worker to come. Even if they're only coming every month, every six weeks. None of that is happening. All it needs is somebody to pop in and say, "I've come to read your blood pressure. Let's have a look at you." That's all it takes. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

2. Physical Enablers of Avoiding Hospital Admission

Preventative Medication

Participants perceived that, once established, their medication was contributing to the control of their condition/s and helped them avoid hospitalisation. Moreover, as described by Patient-8, participants felt their medication was working well and didn't require much thought:

> *I haven't [been to hospital in the past 12 months]. The tablets are working. (Patient-14, female, 63 years old)*
>
> *Oh, aye. I couldn't survive without that [medication]. I mean that's… I'm being honest. I couldn't survive without it. (Patient-3, male, 73 years old, 3 x hospital visits prior to interview)*
>
> *Why I haven't been admitted into hospital? Because I haven't been ill enough. Fortunately. And... Everything has been caught in time. I mean, I'm on so much, what I would call, preventative medicine. (Patient-1, female, 71 years old)*
>
> *Well, I think I take my medication for granted, that it was helping. (Patient-8, male, 89 years old)*

Daily Living Aids and Adaptations

Some participants recounted that they felt their daily living aids such as adapted chairs, mobility walkers, bath aids, bedside trolleys, walking stick, alarms if they fall, adapted showers, stair lifts and commodes helped them within their home and reduced their need for hospital admission:

> *Aids. Your chair, your walkers. We have bed aids. We have the carers coming in three times a day. We have us coming in at least once a day. We have a bath aid. We have everything we possibly can. (Granddaughter of Patient-6 Male, 96 years old, 12 x hospital visits prior to interview)*
>
> *Well, I can do the things I usually like to do. I can still move around. I'm limited in the distance I can walk. But I don't have great difficulty about doing the walking, as long as I've got my Zimmer. (Patient-8, male, 89 years old)*
>
> *I… Have a shower. And I can manage that perfectly well. The wet room has been adapted with lots of things to hang on to. And a seat as well. So that's not difficult. (Patient-8, male, 89)*
>
> *Getting rid of the bath was the first thing. Putting the shower in. Then the stair lift. And I also bought a commode. A very nice one, actually. The downstairs loo - which is there should you need it, by the way. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

Limitations

Resting when feeling tired or unwell and knowing their limitations were enablers of avoiding hospital admission described by participants in the interviews:

> *I mean by just like what I say. Keep it to your limitations, do what… Do what you can do, and don't do what you can't do. (Patient-2, male, 90 years old)*

> *And I know that if I'm doing extra work with preparing for people coming and sorting myself out for people coming, then I get puffed and I need to sit down. But I just come and sit down until I feel okay again. And I get on with it. So I suppose by working within your limits, but then… As you do… I do less now than I did, so it is working within your limits, really. (Patient-5, female, 91 years old)*

> *But, as a rule, I just rest. I just listen, I guess, to what my body is saying. If it's saying you've overdone it, then I just try and rest. (Patient-12, female, 58 years old)*

Additionally, Patient-21, felt that avoiding people when they were ill helped her avoid the onset of her asthma or hyperventilation attacks:

> *Well, if I went somewhere… And one of them turned in and – oh, I've got cold. I get up and go. I wouldn't stay. I just leave. I say, "I've got to go. I can't stay." I wouldn't take that chance. I've done it before and I've ended up worse. Our [daughter] saw me have an attack, and she was flabbergasted. (Patient-21, female, 58 years old, 5 x hospital visits prior to hospital)*

Lifestyle

Healthy eating, having a routine lifestyle, getting some exercise and/or fresh air, avoiding smoking and alcohol, and taking things slow were the lifestyle enablers of avoiding hospitalisation mentioned by participants:

> *I think it's important to me to get a measure of exercise every day. And most of it naturally comes... Naturally, because I push my Zimmer to the post office shops each day. Most days, anyway. (Patient-8, male, 89 years old)*

> *That, and keep a clean life. You know, don't smoke, don't drink heavily. I don't drink heavily at all. I don't drink at all, hardly. (Patient-2, male, 90 years old)*

> *Well, fresh air. Routine. Doing certain things at a certain time. Keeping to it. Sort of, a regular pattern to your life. Going to bed at certain times, getting up at certain times. Meal times - regular meal times at certain times. A general pattern to your life. And provided that's adhered to, you can tick along. Anything different to that, if I've got to go to hospital for something or... You know, then it takes me a day to recover from that. So I think it's the general pattern. A routine lifestyle. Moderation in all things. Moderation in all things. And do everything slowly. Do everything slowly. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

Furthermore, Patient-12 described being aware of the cost of her cancer treatment as motivation for her to keep herself healthy:

> *So that is, I suppose, partly why I feel that I have to do as much as I can to keep me healthy, so that that doesn't happen. I mean, sometimes you can't control it,*

because you can't control your bloods. But, yes, I am aware of the cost. Of keeping me alive. (Patient-12, female, 58 years old)

3. Coping Strategies

Acceptance

Patients described a number of coping strategies they used to deal with being a high risk patient, including acceptance. This involved acceptance of the effects of old age and/or their health condition/s, and accepting that there are things they can no longer do, and most participants described trying to get on with a normal life:

Not a problem. It's… It's a question of… My dad… My father said… He lived until he was 89. And he said to me… He said, "[Name] oh…" He said, "Old age is alright if you learn to live with it. If you learn to live with it." And that's an absolute fact. (Patient-2, male, 90 years old)

I feel a frustration at not being able to do some things. Like changing a light bulb. I'm limited in what I can do. But I accept that (Patient-8, male, 89 years old)

Actually, good. I feel as if I'm in good health. My… The way I look at it is I live with this condition – it's just part of me. I do what I have to do to control it. But I try not to let it interfere with what I want to do. I mean, physically it does affect me slightly because I get more tired and… Sometimes you just have to listen to your body and just accept that you can't do what you're doing today. But, as a whole, I feel… I do feel alright. (Patient-12, female, 58 years old)

You see, I used to go to bed until 12 o'clock. And sleep fairly well. But when I got up and made my breakfast, and then had to go to the toilet to empty my bladder. And then I started looking at a situation where as soon as I got up, I had to go straight to the toilet. And then I started to have to go through the night. It's just something that happens to you with age, you know. Some people get……prostate and… And when it first happens, you think about that. But that didn't happen, so I just got on with my life. (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)

I feel not bad. Because I'm not taking it out on anybody. I just suffer and get on with it……..I've got to try and stop myself going mad and try and hold it together. (Patient-10, male, 64 years old)

On the contrary some participants did not describe accepting their health concerns, Patient-4 for example, felt that she would push herself to do a little bit more than her limitations. Moreover, Patient-11 relayed a scenario where she had pushed herself too far and it had resulted in a painful fall. Similarly, Patient-8 described a fall that occurred as he thought he was more able bodied than he was:

If you do lift something and if you turn funny, yeah, it goes "I'm here. I'm still here." You know. But up here I keep saying, it's in my mind. It's in your mind. You're alright, it's in your mind. (Patient-4, female, 76 years old)

You know, the stuff you… Hydrocortisone, sorry. So I've done that with one leg, tried it, and thought I would do it on the other leg. It was during the night, about three

o'clock in the morning. And it was hellishly itchy. So as I always do, I have a chair with lots of cushions on, which is at an angle. I'm all organised. And I once put a towel on top of that and I had… And I put my leg up to do it. And that's why I bended of course and… Sometimes it gets too painful for. So I put my left leg and fell over. I knocked the trolley that I have with all of my gear on it – which went sideways and the wheel bent into my stomach. And everything that was on the trolley lay on the floor. How I… I didn't lie on the floor – I was sort of suspended over the trolley. Oh, it was painful. And I thought, "Should I tell [Daughter] because I'm sure to get told off." What were you doing? But I was really too tired in this. So I did fall. (Patient-11, female, 87 years old)

Oh, the second time I fell, I had been careful in the house for quite a while. And I thought I was just beginning to get quite a lot better in the house. And my wife was out, and I wasn't supposed to touch the washing – but the washing was nearly dry. And it came on to rain. So I tried to… I decided… I went out and it was too wet, so I didn't bring it in. But I went in myself to get myself dry and forgot the… We had a ramp made out of a……And I forgot about it. And tripped over this flipping board and fell full length into the entrance of the door. And hurt my shoulder again. (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)

Positive Reinterpretation and Growth

Participants felt that positive reinterpretation and growth, including positive thinking and learning from past experiences were important when coping with their health conditions:

A long time ago. When my third… My third son was born. I nearly did [have a nervous breakdown] after that. And from then on, if I get down, I get down. You know, I'm going there again – and I fight. I fight. I fight for everything. (Patient-4 Female, 76 years old)

I would like to think I cope well with it. That's… I try to be positive about it. I just think that it is… We just share a body, you know. It can be a little bit of an inconvenience sometimes, but… That's about it, really. (Patient-12, female, 58 years old)

Yeah. I think [Husband] is amazing, because he just… He just… He's well aware of his condition, but he just did… He just gets ill, and then just pops up again. And everyone laughs about it. He just… [GP] thinks he's got 18 lives. He's just got… He's just tremendously positive. And because he's too… And he's stubborn. Which is good, because if he wasn't stubborn he wouldn't… You know. (Wife of Patient-13, male, 85 years old)

But you can't go on living, thinking you're going to be falling down all the time. I mean, you've got to be much more positive than that, as I say. Well, right – I'm going to do this, I'm going to do that. (Patient-5 Female, 91 years old)

You know, you've got to get on with it and think positive. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)

However, a few participants described struggling to keep positive about their health:

It's difficult. Because, you see, when you're feeling depressed it's just go for a hobby. But what can I do? I would like a little fish bowl – floating in a little thing here. I can't care for them. I would love a huskie. They're lovely dogs. But I can't look after them. Some people collect stamps – I can't……I couldn't put them in an album. Things like that. That doesn't work. (Patient-10, male, 64 years old)

He [husband] brought me home from hospital and after coming out of intensive care and everything – I was too frightened to be on my own. I was just sitting there, watching telly. And I kept on thinking I'm like a muppet here. You know, this is just a muppet life. (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)

Mental Disengagement

A few participants recounted using mental disengagement techniques of getting out the house to help them think about their health less:

Sometimes… Yes, I think the best thing is going out in the car somewhere and then getting out of the car and going for a walk with my husband. (Patient-4, female, 76 years old)

But it gets me out into the world. Because you've got to try and get out and about. Because if you're feeling under the weather, I feel stuck in the house anyway. With bad roads, if not bad payments and stuff like that. So you get out in the wheelchair (Patient-10, male, 64 years old)

Focus and Venting of Emotions

A few participants described venting of emotions as an important way to cope, either through self-management or with other people:

Oh, he's horrible to me on a bad day. (Granddaughter of Patient-6 Male, 96 years old, 12 x hospital visits in the past 12 months)

So the health is okay, but I mean… I get by. I do everything for myself. And I drive, so… I can't… In some ways, I can't complain. On down days I do complain to myself. (Patient-5 Female, 91 years old)

It was noticed that it was mostly patients who had not had any unplanned hospital visits in the past twelve months that described having coping strategies

4. Support Networks

Support from Family

The majority of participants described a social support network of family that contribute to helping them cope with their health conditions by physical support mechanisms including acting as carers, organising medication, being someone they would call when they did not feel well, doing the food shop or giving participants lifts to the hospital:

And my uncle does his shopping as well. Today. And I do little bits and pieces if I'm going anywhere, and bring that in. So... He gets plenty help and support. (Granddaughter of Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

And I'd just got back from the Freeman and the phone rang again, and it was the on-call oncologist saying, "Are you alright?" And I went, "Yes, I'm fine. I've just come back from the hospital. Why?" "Well, we're sending an ambulance for you, because your bloods are all over the place. We need to admit you. You're going to have to come in for some IV fluids and… To get you stabilised and everything." And I went, "You're not sending no bloody ambulance for me." So I said, "I'll ring my daughter." And he said, "Well, you've got to get back here." (Patient-12, female, 58 years old)

But, like, when my daughter comes, we can sort… We cancel the carers sometimes. But it's quite nice to sort of, you know… Your time is more your own, sort of thing. (Patient-15, male, 85 years old)

My granddaughter here, who's… She's a nurse. She's on the central photograph. She's working in the new hospital at Cramlington, and she's now working at the RVI. And she takes care of me. My medical problems. And I get these dosette boxes, which contain a lot of drugs. And they… Near the end of the month, she'll phone the surgery to tell them to… I'm running short and they… Make sure the next one is there. (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)

It was very late one night, and……And I was taking my tablets round, and going to bed about 12. But this night… I fell against the doors. I was going to phone my son. I must have felt unwell. And I thought I better phone my son. But I didn't get to the phone. And I fell. (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)

For participants who lived with their husband or wife, their spouse was found to play a key role in looking after their needs:

He's [husband] been very, very supportive. And yet he has problems of his own. Which, if you do an interview with him, you'll find out. I'm fine. With [Husband]'s help, we get through, don't we? (Patient-1 Female, 71 years old)

Oh, yes. I feed him, look after him. Examine his legs every day to see if his cellulitis is back. (Wife of Patient-7, male, 78 years old)

The enablers [of avoiding hospital]? Well, my wife, again. (Patient-8, male, 89 years old)

I look after him. I make sure he's okay. (Wife of Patient-16, male, 78 years old)

And I think I've been lucky, you know. Yeah. Mostly because [Wife] looks after me so well. (Patient-17, male, 80 years old)

I think because me, myself… If I was here on my own, I don't… I wouldn't cope properly. Because [Husband] is here, I cope a little bit better. (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)

Additionally, the spouses that contributed in the interview generally all had a good knowledge of their spouse's health conditions, medication and hospital visits while generally the participants had a low knowledge:

> *He's got atrial fibrillation but that doesn't seem to bother him at the moment. He gets a lot of chest infections. That's the main bugbear, yeah. (Wife of Patient-13, male, 85 years old)*

> *But I knew what I'm taking and what they're for, but I can never remember, you know. And [Wife] can usually rhyme them off for me. (Patient-17, male, 80 years old)*

Patient-20 commented that since she does not have family to support her she would feel she would have to go into hospital for something like flu as she has no family to look after her and there is no longer a small local hospital that she could go to instead*:*

> *If you've got 'flu or something and you're in bed with 'flu, it's good to be in a care situation where you've got somebody coming to look after you. Well, that's alright if you've got somebody like, you know, a family member. But if you haven't - like me - where do I go if I've got 'flu. You know, what happens to me? I don't really want to go into hospital for 'flu. But if there was a unit - a small unit - where I could go for three or four days, that would be fine. But there isn't. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

Support from Friends

Support from friends and neighbours was described by participants, including helping out if needed, such as in the instance of Patient-8's neighbour who is second in line for emergency button alerts, or even ringing to check how the participant is coping:

> *They don't come in and out, no. Never have done. But they're good neighbours. And the lad next door, he said to [Wife], he said, "If you need help any time, day or night, ring me up." (Patient-2, male, 90 years old)*

> *I know that they are there for me. I'm there for them, and they are there for me. They are wonderful neighbours. (Patient-4, female, 76 years old)*

> *[Name], next door but one, he phones every morning. And this lady next door phones. They all phone in the morning to see I'm alright, you know. They see the ambulance that many times, you know. (Patient-18, male, 79 years old, 12x hospital visits prior to interview)*

> *Well, we have friends from the support group. Like, [Name], who's the… She rings us up every fortnight when he's due for the… For the meeting. And then [Name], the coordinator, she's been to see us a lot. (Wife of Patient-13, male, 85 years old)*

> *You know, if you… And he's [neighbour] number one on the… Number two, after me, on the red button alert. The ready call, or whatever it's called. There are one or two people that you could rely on for help on there. (Wife of Patient-8, male, 89 years old)*

A few participants described situations where neighbours had actively helped them such as checking they are settled at home after returning from hospital, driving them to their GP appointments, or preparing meals for them:

> *My neighbours are wonderful. They came in and helped, to allow me to be at home. (Patient-12, female, 58 years old)*

> *My neighbours take me in the car [to the GP surgery]. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

> *Well, [neighbour] and his wife do nearly everything. His wife will cook us four meals a day for the freezer. She'll cook four meals for us that we can freeze for the days when I can't cook or haven't the time to cook. (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)*

However, a few participants recounted that they did not have neighbours that can help them out if necessary:

> *I haven't got a neighbour and no-one that can pop in. (Patient-5, female, 91 years old)*

> *And when you're my age you're on your own all day, for days on end I see my daughter but nobody else. And occasionally next door, and she's not very well. And I don't want to talk about the neighbours on this side. (Patient-11, female, 87 years old)*

Spouse's Burden of Responsibility

Some of the participants whose spouses had become their carers described the strain that it had on their spouse including the burden of responsibility to do everything. Moreover, the wife of Patient-13, aged 81, described getting tired from looking after her husband:

> *I'm principal carer, really, yeah. (Wife of Patient-13, male, 85 years old)*

> *Yes, my wife has become my carer. (Patient-8, male, 89 years old)*

> *It puts a lot of strain on her. More than it should. But... Nobody else can do it as well. (Patient-13, male, 85 years old)*

> *Having him at home is friendly on my day off, but quite stressful otherwise because... You know, we used to, in years of good health, say, "Right, well, this is what I'm doing this morning - what are you doing this morning?" "Oh, I don't think I'm coming home for lunch. I'll probably see you at evening prayer." You know, and so it was very much, well, can you just do such-and-such while you're in... If you're going to Hexham, can you do such-and-such? But now it's really... Somehow I've got to make sure everything happens. So it's quite a stressful life. That's a fair summary, isn't it? (Wife of Patient-8, male, 89 years old)*

> *I look after him. When I go out... Sometimes I just... On the respite, I just go to sleep. I have a sleep when the carers are here sometimes, because I do get very tired. Because I am 81. So... I do get tired. Especially if we have... I don't sleep*

> *very. And, of course, I'm always awake for [Husband], really. So I don't sleep very well. And so I do get tired. (Wife of Patient-13, male, 85 years old)*

Moreover, Patient-21 explained that her husband had performed CPR on her seven times and had retired early to look after her:

> *My husband has done resus' on me seven times. So it's very hard. You know, to be like that, when you… Luckily he's a good… He was a firefighter, so I'm lucky he's able to do it. But if it had been anybody else, I don't think I would have survived it. If he hadn't have been there. But he retired, so he could be with me. Because I was collapsing in the home. Just being out, on the floor. I didn't even know I was out. (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)*

5. Continuity of Care and Attitudes towards Health Professionals

Preference for a Particular GP

The majority of patients recounted that they try to see the same GP, with some participants mentioning that this is usually their nominated GP:

> *Or she'll ring up and say, "How is [Husband]?" Or... He says she's amazing, you see. She's got quite a relationship with him. I think he's quite a pet.. (Wife of Patient-13, male, 85 years old)*

> *I have a nominated GP. Who was the one I nominated when I first came. And she's the one I've seen most regularly. But I occasionally see her other partners, who I like. (Patient-8, male, 89 years old)*

> *I thought I would do and see the doctor I'd been given, the new doctor. Because if he's got a responsibility for me, I would like to see him. And I'm sure he would like… Well, I don't know that he would like to see me, but I thought it was right that he should know who was on his list. So I went to see him. And he's the one that I've been seeing recently. (Patient-5, female, 91 years old)*

Reasons participants stated they see the same GP included allowing for a patient doctor relationship to evolve, ability to build trust, feeling their GP has a good knowledge of their health, and because they are not rushed. Habit and time saving were also mentioned by participants:

> *It's something I've done, really, out of habit. Because I think it's best if one person gets to know you. Because otherwise you've got to sit there and tell them everything, haven't you? I know it's on your notes, but they haven't got times to read a great pile of notes. So, yeah, I... I like it and I find it very accommodating. And so, yeah, I do stick to the same one. (Patient-1, Female, 71 years old)*

> *She never lets you know that she's very busy. Never. I mean, when you go in to see [GP] you are not rushed out. You are not rushed out. She… She lets you go. She says bye-bye when she realises that you've… You're finished. Yeah. She's very good. (Patient-4, female, 76 years old)*

I would try and see the same doctor. Yes, because they get to know you and you get to know them. You build up some trust and… So I'm getting to know this new doctor – new for me. And he's been very attentive. But then, the other one was. And the one I had before that was. (Patient-5, female, 91 years old)

But over the time, especially if it goes over the years, that GP gets to know you better and knows exactly… Whereas if you're just seeing the GP once in a blue moon, a different one every time, I don't… The continuity is not there. They look at the screen – oh, yeah, I see you've been prescribed this. Right, we'll give you that. But if you see your own GP, he'll discuss it. He does take time out to talk to you. (Patient-14, female, 63 years old)

Difficulties in seeing the same GP mentioned by participants included doctors working in multiple surgeries, high demand for a particular GP, or the GP being absent:

The only thing is… If you want to see [GP] you might have to go up to [the other surgery] (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)

That's the only fault I've got here, aye. You can't see the doctor you want to see. (Patient-15, female, 75 years old, 5 x hosptial visits prior to interview)

Well, [GP] has been poorly, so I haven't seen her for quite a… Well, she's back now and we're seeing her now. So it's fine. But, I mean, she has been off for quite a while. (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)

Some participants said that they did not have a preference for a particular GP, with some participants feeling that they would receive the same care from all doctors, while other participants depend on which doctor is available at their local surgery or who is available for house calls. Moreover, Patient-17 felt that seeing the same GP is rare due to the new system used by GP surgeries:

No [preference for particular GP]. I mean, a doctor is a doctor. (Patient-7, male, 78 years old)

No. If it did, that means there's something wrong with the other GPs. So I'm assuming that all GPs are… At least the minimum standard of knowledge. Medical knowledge. Obviously some will be more knowledgeable than others? But as along as they've got the minimum requirement, I'm prepared for them to treat me. (Patient-16, male, 78 years old)

No I just ask for a doctor. They do come to the village twice a week. They come on Tuesday mornings and Thursday mornings. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)

No. Just whoever is on call. (Granddaughter of Patient-2, male, 90 years old)

The new system, which I think works, is that you ring up a… One of the GPs will ring you back and ask what it's all about. And they make a decision then whether they need to see you or not. And usually, whoever it is that had rung you, is the person that you go to see. But I think increasingly I've… Just about everywhere, you know, seeing the same doctor twice is rare. (Patient-17, male, 80 years old)

Medical Reviews and Routine Appointments

Participants described regular check-ups with health professionals including district nurses, nurse specialists (Macmillan nurses, diabetes nurse), physiotherapist, consultants, oncologists, phlebotomists and chiropodists. Regularity of visits ranged from every other day to yearly checks-ups depending on the condition. Participants recounted that they had regular check-ups for their diabetes, breathing tests, cancer checks as well as bandages/dressings being changed and checks for bed sores:

> *Conditions? I have ulcerated legs. One is jolly nearly clear now, the other one is diseased and is dressed regularly by the district nurses, three times a week. It's actually doing very well. The consultant is delighted with the way they have looked after it (Patient-8, male, 89 years old)*

> *I'm not due to see [consultant] again until February. But I'm seen nearly every four weeks by the nurse specialist. (Patient-3, male, 73 years old, 3 x hospital visits prior to interview)*

> *Yes, I see... I see a diabetic nurse, three monthly, which is more than my previous practice. I also see somebody who does feet six monthly. (Patient-1, female, 71 years old)*

> *Yeah, when I have to get my thyroid blood tests done, I have to go to the COPD clinic, still. And then, of late, they've brought in orthopaedic… She's not like a consultant or anything, but specialises in it. And I saw her, and she's very good. You know, they do have the different clinics and everything. (Patient-14, female, 63 years old)*

> *Yeah… No, every other month officially he's meant to see the consultant. He saw him last week because he had a lot of extra pain. But he has the radium-223 injection for six months. So it's… He's just had the third one. He's due the fourth one on the 21 of February. So… It's a bit of a… (Wife of Patient-13, male, 85 years old)*

> *No, they did it for us. Well, he's on continuing care. But we have carers and we have… The district nurses have been in a lot because he had a heel that wouldn't, sort of, heal. And a… For a year. And also we have a MacMillan nurse and a MacMillan physio. And now we've got a MacMillan helper. We've got a great GP who comes in quite regularly, or rings us. So, you know, we really have amazing care. (Wife of Patient-13, male, 85 years old)*

Lack of continuity of care was mentioned by a few patients, including seeing different nurses during routine check-ups, with some participants mentioning that nurses are pushed for time:

> *But you get a different person [nurse] on the whole now. But the girls who work there, apart from one – and I don't think she even will be… You see, people move round so much nowadays. It's like doctors. You only have a contract for a year or… You don't have the opportunity of seeing the same person, is what I'm saying. But, on the whole, the nurses are canny. But pushed hard. They haven't… They're only here for ten minutes. (Patient-11, female, 87 years old)*

Aye, different ones [nurses] every day. But they come Monday, Tuesday, Wednesday, Thursday, Friday and they're different during the weekend, you know. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

These same participants also recounted that there was quite high turnover of doctors within their GP practice which they felt affected continuity of care. Moreover, a few participants felt that the volume of paper work involved in today's healthcare had a negative effect on continuity of care and also meant that patients had to keep relaying their health concerns to a number of different health professionals:

Well, there's [GP]. And they change so often. You know, you don't… You just don't have a usual. They change every six months. And you never know who's coming in next. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

Everything is paperwork and everything has… Instead of being on particular interview or one particular appointment, you're moved from person to person. And each person has to listen to the whole thing over and over again. Which is wasting time in any case. (Patient-11, female, 87 years old)

Trust and Confidence in Health Care Professionals

The vast majority of patients felt that they had received excellent health care, and described health professionals, including GPs, nurses, physiotherapists and consultants, very positively. Generally, participants felt that health professionals were doing their best to look after them, and they described having trust and confidence in their health care providers, with Patient-15 in particular feeling that her GP was like family:

Because the doctors... The doctors are good, the nurses are good. They look after you. (Patient-2, male, 90 years old)

I can't condemn any of them [Doctors]. I speak as I find. I'm being honest here, I can't find a fault with any of them. (Patient-3, male, 73 years old, 3 x hospital visits prior to interview)

So I'm well covered on the diabetes side. And they do it… They're doing their best to get the irregular heartbeat… But I've had that over many, many years. (Patient-5 Female, 91 years old)

She's [GP] just amazing. She really is. And the district nurses are wonderful as well. (Wife of patient-13, male, 85 years old)

She [physio] knew exactly what my problems were. And she was... Well, she sort of... I got helpful chat from her. Advice, really. (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)

I just got my trust in him. You know? Like I say, he's really... You know when you're talking to family, you trust your family, don't you? When I talk to [Name], like I said before, he's like family and I trust him, you know. (Patient-15, female, 75 years old, 5 x hosptial visits prior to interview)

A few participants, however, described a lack of confidence in their GP. Interestingly, these participants had both had eight or more hospital visits in the 12 months prior to their interview. Patient-18 described wanting a second opinion after disagreeing with his GP, while Patient-20 felt abandoned by her GP and that phoning for ambulance instead would give her the reassurance she needed, and also commented that she felt grateful to have routine appointments with specialists in hospital who she felt she could trust:

> *Well, some of them do. Some of them. But that [GP] doesn't. There's nothing the matter with you – there's two paracetamol. I said, "Well, what's the matter with me when you're giving me two paracetamols?" And then I said, "Can I have a second opinion?" "You don't need a second opinion." Aye. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)*

> *And in the end they said, "Well, look... We're doing all we can. We've done all we can for you now, it's up to... That's it." And so I feel a bit, you know, abandoned, really. And so... So, really, if I do feel ill the GP, really, is almost the last person I should ask for help. I think I'm more inclined to phone 999 and get the ambulance service. Because at least I get - from the paramedics that come, at least I get a proper examination. You know, I get my blood pressure taken, I get my stats taken. I get an ECG in my heart. And they do all that in the house. And so at least I get a proper examination, which I don't get from the GP. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

> *So that's... It's a very cursory care that I'm getting from them [GP]. I'm just grateful that eventually I shall be going to the RVI to see the consultant, and I shall by going to the Wansbeck to see the pulmonary people. They're the people that I put my trust in. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

Consistency of Care

A few participants recounted feeling that there was a lack of consistency amongst the care provided by different GPs which affected the care they received and the trust and confidence they had in that particular GP. Consistency of care amongst GPs, however, will depend upon the level of experience of the GP:

> *There's another doctor that… I just have more faith in, I've got to say. I do feel… More faith that they can deal with whatever is wrong with me. Better than some of them, you know. Yeah, I do have more faith in them. And I could speak to him. He's been there so long, he knows the… And soon enough… I just have more confidence – far more confidence in seeing him. (Patient-14, female, 63 years old)*

> *The Chinese doctor was brilliant. She was spot on. As she was with this… I imagine, South American doctor, who seemed… Just wasn't very good. But he seemed to be the senior doctor. I don't know where she was… Talking to him around. And he… He… They were talking about his medication, and he wanted to break a slow release drug in half. Which is terrifying. It could kill him. And we both said, "No, you can't do that." (Patient-13, male, 85 years old)*

6. Decision Making and Responsibility

Patient Decision Making

Most participants recounted situations where they had been involved in making a decision regarding their health, such as deciding to go home from respite care as described by Patient-6, or deciding against moving out of their house as described by Patient-18, which are both examples of patient decision making in conflict of the opinion of a health professional:

> *And there was no heat on in the place. I said, "I'm not stopping in there, doctor." She said, "Well, you might fall. And we don't want you to fall. And get a broken arm." I said, "I don't want pneumonia either." And I came home. And I've been home ever since. (Patient-6 Male, 96 years old, 12 x hospital visits prior to interview)*

> *The nurses and the social workers and… I tell and give it [his house] up. Give it up, give it up. I said, no, I'm not giving it up. (Patient-18, male, 79 years old, 12x hospital visits prior to interview)*

A few participants described scenarios where they had made the decision to stop their medication. Unlike Patient-5, both Patient-7 and Patient-16 recounted that they had not yet informed their GP:

> *They were very accepting at the surgery that if I felt that I didn't want to take them [statins], that was my responsibility and my choice. And, you know, afterwards I discussed it with them. Just as I don't have a 'flu jab – because that's my choice. I used to have it, and then one winter I was… I was very ill after I'd had the 'flu jab. They say you can't get 'flu from having the jab, but I had a very bad bout of 'flu, having had the jab. And so I thought, well, if I get with having the jab, I can do without it. Because I don't see overloading myself with medication, if I don't have to be overloaded with medication… (Patient-5 Female, 91 years old)*

> *I haven't seen them [GP] yet. I'm going to get that checked next week. I've only been off them [statins] for three weeks or so. (Patient-7, male, 85 years old)*

> *And I've reduced that [sulphasalazine] myself, and I haven't even told the doctor. You're the only one other than my wife knows that I've reduced it from four, twice a day, to three, twice a day. And nothing has changed. I'm still feeling great, as far as that's concerned. (Patient-16, male, 78 years old)*

Moreover, some participants described deciding against having an operation, or going for a colonoscopy. However, in the case of Patient-12, she recounted that she found it difficult to be the one who made the ultimate decision regarding her lumpectomy operation:

> *I said, "My opinion is..." I said, "If I'd been 40-years old, I would have the operation tomorrow." But I said, "At my age now, going under anaesthetic and that, and going through an operation, I'm not so sure. I'm not so sure." And he said, "You're right. You're right." He [consultant] said, "I think you're right." So that's why we went on the warfarin, aye. (Patient-2, male, 90 years old)*

The colonoscopy. I mean, it looked clear to me, but the consultant… No, I've forgotten. He was pointing out there was a scar tissue, I think he said. And they did the biopsies while the camera was there. But it's… Everything is… It's so good now, when I get the letter asking to go for another colonoscopy, I'm seriously thinking of saying no, thank you. (Patient-16, male, 78 years old)

The decision as to whether you have a lumpectomy or… Is yours. You know, and that was… That was the other bit that I found quite hard. I wanted… I really wanted them to say, well, I think this will be best. But they can't do that. That decision is your decision. (Patient-12, female, 58 years old)

Family Decision Making

A few participant interviews revealed scenarios where family decision making was involved regarding the participant's health care. The granddaughter of Patient-6, who was his main carer and a midwife by occupation, described two instances where she had made the decision to stop her grandfather's medication as she believed it was doing her grandfather more harm than good. While the wife of Patient-7 made the decision to call the GP and have her husband admitted to hospital as she felt she could no longer cope with looking after him:

But we did speak to the doctor and they actually stopped some of his medication and things. So... He'd been put on metolazone for the chest pain. But it was making him very unsteady on his feet. And certainly wasn't really doing much for the chest pain either. So we stopped that. (Granddaughter of Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

Well, when we came in the next day, the Monday morning, he was confused. He was agitated. He'd taken the wrong medication. He just wasn't right. So I rang the GP, told him what I was doing. I rang to Balliol and got an emergency place. I told them I was stopping the MST because I felt that that was contributing to his wellbeing being poor. (Granddaughter of Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

I actually phoned the doctor to get him admitted, because I knew I couldn't cope at home if he had another fall. (Wife of Patient-7, male, 78 years old)

Moreover, the husband of Patient-21 commented that there was an occasion where he had disagreed with the decision of the practice nurse regarding removing his wife's prescription of oxygen:

Because, [Nurse] two months ago said, "Oh well, we might stop the oxygen." And I said, "No, you won't." I said, "What happens if you take it off us, she has an attack, although it might be five minutes… And I've got to give her five minutes' oxygen… And she could be dead." I said, "Are you going to take responsibility for taking it off her?" I said, "That's what it's there for." And he went, "Oh, I take your point." (Husband of Patient-21, female, 58, 5 x hospital visits prior to interview)

Shared Decision Making between Patient and Health Professional

A few participants described instances of shared decision making and responsibility between themselves and their GP or specialist, where they had discussed their healthcare together to agree on a particular approach to treatment. Moreover, a few participants mentioned that they felt that there could be more open discussion about treatment with their GP compared to in the past. However, Patient-20, who had previously explained that she had lack of trust and confidence in her GP, had a negative view on modern doctor-patient interaction and felt that patients were more likely to question the doctor now as the doctor is more like a computer than a person:

> *I know what is likely to go wrong with myself at any given stage. And... I can work with [oncologist] and the general planning and work out... (Patient-13, male, 85 years old)*

> *Yes, I think the fact that it's left to me now to decide whether I want to go back to the Freeman for any sort of treatment or decision or whatever. It's up to me. And the GP here. Between us, to decide if we wanted to do that. (Patient-8, male, 89 years old)*

> *I think patients are a little bit more on the ball now than they were then. I think they were more prepared to accept what the doctor said. And do what the doctor said. Nowadays patients will question what the doctor said. Mainly because they don't feel that it's a person there. They feel they can question the computer, whereas they couldn't question the old-fashioned doctor (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

7. Attitude to Health care

Access to GP Appointments

There were mixed opinions on the access to GP appointments, with some participants feeling that access was easy and that they usually receive an appointment that day or within the next couple of days. While other participants felt that access to GP appointments was unsatisfactory at times with either long waiting times for a call back from their GP or for an appointment, and with GP surgeries being understaffed as described by Patient-7:

> *I would probably get one [an appointment with GP] tomorrow morning (Patient-3, male, 73 years old, 3 x hospital visits prior to interview)*

> *Oh, I can get one [appointment with the GP] within a day or two, usually. (Patient-8, male, 89 years old)*

> *If you can't get an appointment that day, you've got to phone up the next day. (Patient-16, male, 78 years old)*

> *It's [access to GP] okay up to a point. We've had my ear filled up with wax. And I rang up, and I couldn't get an appointment for nearly three weeks. And I thought... I said, "Hang on, this is only... This is only was that needs cleaned out. Well, I mean, for me, it was a trifle thing, like. But I still had to wait. I've got to go tomorrow. (Patient-2, male, 90 years old)*

Latterly you would have to think in terms of a fortnight [for a GP appointment], unless you were really ill. (Patient-5, female, 91 years old)

Well, these two - there needs to be more of them [GPs], because you can't get a doctor at the minute. (Patient-7, male, 78 years old)

The NHRPP

The majority of participants were unaware of the NHRPP and why they were registered on it. Additionally, Patient-15 commented that she did not know that she was considered 'high risk', even after having five unplanned hospital visits in the 12 months prior to the interview, while, although Patient-13 had not heard of the NHRPP, on the contrary he considered himself to be high risk:

To be fair, you mentioned it [NHRPP] in the letter, and we talked to each other and said, well, we didn't know you were on a high-risk patient programme. (Patient-17, male, 80)

I've never heard of it [NHRPP]. (Patient-13, male, 85 years old)

No. I didn't know I was high risk. (Patient-15, female, 75 years old, 5 x hospital visits prior to interview)

No. I assume I'm high risk. (Patient-13, male, 85 years old)

Unlike the majority of participants, Patient-14 was aware that she was registered on the NHRPP and she felt that it was a good idea and that it had improved her access to getting an appointment with her GP:

I think… It's [access to GP] a lot better for me since I've been put on this list [NHRPP]. I think I would have had more trouble trying to get an appointment where it would end up… I would eventually say I need an emergency appointment. (Patient-14, female, 63 years old)

Attitude to going into Hospital

All patients recounted that they preferred to stay at home compared to going into hospital and participants recounted that they enjoy being at home:

Being at home? I love being at home. (Patient-5, female, 91 years old)

Well, home is the best. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

How do I find staying at home? Oh, champion. (Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

Participants, however, felt that if they were really unwell then they would need to go to hospital, and this was influenced by a health professional making the decision to admit them. Patient-4 and Patient-21 particularly did not like going into hospital, and Patient-4

described that she found it uninteresting and had a previous negative experience on ward two in The Freeman Hospital when her mother passed away:

> *I would go into hospital if I really had to. I mean, obviously, if you're in a position where you're really poorly, then hospital, really, is the best place possible. So it would… It depends on the circumstances, obviously. Because there's times when you really don't have any choice. And you have to just accept the fact that you've got to go into hospital. (Patient-12, female, 58 years old)*

> *Well, only if it's necessary. And somebody more… Experienced, educated, should make that decision as to whether I need to go to hospital. But if I think I don't need to go to hospital, why should I go? (Patient-16, male, 78 years old)*

> *I hate it. It always had… I just hate it. I know I've got to go there because it's the only place I can get sorted. But once I'm sorted, I want to be out. (Patient-21, female, 58 years old, 5 x hospital visits prior to interview)*

> *I just don't like going into hospital at all. I would rather... I would rather be at home, and especially... If there's something wrong with me, then alright. It's not so bad. I mean, when I had the stent implant, I was in the hospital, in the Freeman, for eight days, because they couldn't right the blood and so forth. But there was... There was a reason for it. To go in and... It's because you've had a pain - I know it's the heart but... Just... It's boring. It's boring…….Plus ward two - my mother died of cancer in there and I don't like it. No. (Patient-4, female, 76 years old)*

However, for a few participants the perspectives on going into hospital were much more positive as they felt that the hospital was providing them with the help and attention they needed, although Patient-11 felt that hospital visits were too brief and there was not enough support offered after being discharged:

> *Oh, I find it [going into hospital] fabulous. No problem at all. No problem at all (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

> *Well, it's [hospital] helping me, isn't it? I haven't got attention when I get home, down here, you know. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)*

> *When you have to go, you go. You're very pleased to go, very obviously, because it gives you a chance of living again. And nobody likes it. It's not as easy it was, because you're in and out quickly without enough support. Let's face it. You could do with a bit more support to get you over, because… When you're out there's weeks and upon which time, you're still struggling. (Patient-11, female, 87 years old)*

There were mixed views amongst participants on the hospitals in the North East of England, with some perceiving that the hospitals were good and provided good care:

> *There isn't a single person, either in any of the hospitals I've been - either the Wansbeck or Cramlington or the RVI, from the cleaning lady to the top consultant, have been absolutely magnificent. I could not praise them more highly. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

As far as I'm concerned, Hexham Hospital is excellent. It's excellent. I have no complaints whatsoever about Hexham Hospital. And it's small, it's accommodating. (Patient-5, female, 91 years old)

I think the... Generally speaking, the care in... On the ward, when I've been on a ward, has been excellent. Thoughtful. And all my needs have been met. So it's been quite a good experience. (Patient-8, male, 89 years old)

You know, my experience of all the hospitals around here – I couldn't pick one out and say, well, they're pretty rubbish. I think they've been really competent. And really helpful. And, you know, all of the people that I've seen – you know, for this and, you know, in the operation and… Whatever. Yeah, I thought it was… That's pretty good. (Patient-17, male, 80 years old)

Because if you've got to go into hospital, make sure you go in there [Northumbria Specialist Emergency Care Hospital]. It's super luxury. It's absolutely amazing. I've been in... Well, my wife has spent a lot of time in Nuffield Hospital in Newcastle, and that's a slum compared to... It's nothing like... (Patient-9, male, 96 years old, 1 x hospital visit prior to interview)

However, some participants described negative experiences of hospitals including not being able to obtain the correct pain relief as described by Patient-12, while Patient-18 perceived that there were cleanliness issues. Additionally, there were a number of complaints, including lack of decision making by hospital doctors, long wait times, the temperature being too cold, and hospitals being too busy to cope:

And, unfortunately, it got worse over a weekend and I couldn't get pain relief. Because there was, apparently, only one doctor. All they could give me was paracetamol and ibuprofen. Because there was only one doctor on A&E [in Wansbeck Hospital], and they couldn't get them to… To thingee… With the morphine. And I put in a heck of a weekend that weekend. (Patient-12, female, 58 years old)

I was at Cramlington before this – but, oh, it's a filthy place, Carlisle. Very filthy. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

My experiences of Cramlington have been seeing doctors who didn't know what they were doing. Who… Only wanted to pass it on to somebody else. And… Who have no confidence, apparently, in their own ability to make a diagnosis and for it to… It's as straightforward as that. I mean, I have seen… Supposedly seen the head doctors at Cramlington, who would not make decisions. And that… Passed it all on to somebody else. And, I'm sorry, I don't regard that as satisfactory in a local hospital. (Patient-13, male, 85 years old)

The timeframe that you wait, and Cramlington is freezing. (Grandaughter of Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

You're in there [NSECH] - they want you out before they get in. Have you ever stood...? Been in a queue waiting to get in? I have, at that hospital. In a queue to get in. (Patient-6, male, 96 years old, 12 x hospital visits prior to interview)

Perceived Problems with the Healthcare System

Generally participants were very positive about the NHS, however, some participants recounted experiences where they felt the health care system was inadequate including GP surgeries being more focussed on cost saving than providing health care, communication issues between GP surgery and hospitals, lost medical records, incorrect medication dosages, and lack of staff and staff time:

> *I did used to be on the patient panel. I used to go to meetings there. I did stop going. I started feeling at the meetings that… And I did outright ask, look, this seems to me… To me, more of being dealt with as a business. And not a doctors surgery for care. So I stopped going. I did feel that. I did feel that every meeting was money, money, money and it was more a business. So I just stopped going. (Patient-14, female, 63 years old)*

> *I'm afraid I really don't know. I mean hospital administration or general health service administration and communication from one area to another, you know. GP, local hospital, Freeman - I don't honestly know. It just felt as though... Good, now we're geared up, and something is going to be done about this condition. And then, oh dear, there's a phone call - it won't be this week, it'll be next month. (Wife of Patient-8, male, 89 years old)*

> *Unfortunately, what had happened - I lived in Pegswood, near Morpeth, until I got married. And in those days it was all, like, obviously written - handwritten. Not computer for your records. And they lost an awful lot of my records, transferring over. (Patient-14, female, 63 years old)*

> *And she [GP] obviously misread the letter. And so [husband] was prescribed a really high dose of statins. Which, over a period of about, six to nine months, he lost all the muscle… He was always a strong man – in his arms. And we did ask her… To be fair, we did ask at the GP, and they said, "Oh well, because of his heart problem…" And we said, well, there isn't… I mean, we never got an apology. I'm sure the letter got lost. But, dear… So we haven't taken statins from then. (Wife of Patient-17, male, 80 years old)*

> *The clinics are much shorter, because they've got to see other people. (Patient-10, male, 64 years old)*

> *I mean, lots of doctors say they work part-time. Well, they didn't in my day. (Patient-11, female, 87 years old)*

8. Care and Attitude to Care

Level of Care Requirement

Six of the study participants had carers and levels of care varied from a daily visit in the morning such as the experience described by Patient-18, to more frequent visits of 2-3 times a day, while for Patient-10, due to his Fibrodysplasia ossificans progressiva (FOP) condition, he had carers for 11 hours each day. Participants described carers helping with cleaning,

washing clothes, meal preparation and cooking, showering and helping participants get dressed:

> *She comes in at seven o'clock on the morning, every morning. Except on Wednesday. And she cleans and makes my breakfast. She makes the bed, washing, the lot. And she comes in at seven, and away at eight. Aye, and she comes in now and again to see how I am, you know. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)*

> *Yeah, we have Tynedale care. And they come in every morning for half an hour, and in the evening for half an hour. (Wife of Patient-13, male, 85 years old)*

> *You get one [carer] for… Dinnertime, between half past 12 and 1. And I get one for tea time, about half past 4. At night time… I wanted to get one to come at 12 o'clock, when I used to stay awake until about 12. But the latest they can do is nine. (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)*

> *They come in once a day. At eight o'clock in the morning until seven at night. And they cook all my meals. They get me up, help me to get dressed. And, cook the meal and anything that I really need done. (Patient-10, male, 64 years old)*

Some participants commented that feel they do not currently need help or carers although acknowledge that they may require care in the future, and described instances where they have been independent including doing things for themselves, driving their car, and buying readymade food for the freezer:

> *Going to hospital may be the solution for the condition I happen to be in at a particular time. But if it were just that… A general not wellness that didn't need hospital treatment, then I would… That I couldn't look after myself. Then I would want carers. Because I would neither want to go into a… Into a home. Nor would I want to go to hospital if it wasn't necessary. (Patient-5, female, 91 years old)*

> *I do everything for myself. And I drive, so… I can't… In some ways, I can't complain. (Patient-5, female, 91 years old)*

> *I'm very independent, you know. (Patient-15, female, 75 years old, 5 x hospital visits prior to interview)*

> *They talk about carers going in to give people food and feed them and so on. And get them up in the morning. Well, it's not necessary if you think ahead for that. You know, you can think ahead and say, well... If I'm going to have Wiltshire Farm Foods... They do a very good breakfast. You know, and so you're to get it out of the freezer and stick it in the oven, or the microwave if you've got one. And that's your breakfast. You don't need somebody - a carer - to come in. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

Attitudes to Care and Carers

Participants that had carers generally accepted they needed care and felt the care they received was good. The wife of Partient-13 felt that since her husband has terminal cancer, the care he receives is better than the care offered to people with dementia:

The carers are, in general, very good. And… I appreciate what they do. I don't know whether I can say much more, can I, love? (Patient-13, male, 85 years old)

I'm quite happy with [Carer]. And she does everything. She never has to be told, you know, to do anything. And she puts everything back where she gets it, you know. And that helps me a great lot. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)

We were very lucky, and we've been very grateful. Because we go to... I go to carers, and there's a lot of people that have people with dementia, and they don't get half the help we do. I think the c-word helps sometimes. I know it's not right, but I think it does. (Wife of Patient-13, male, 85 years old)

Patient-3 described that he would prefer to not require care. Moreover, the wife of Patient-13 although grateful to have carers to help her husband, felt that having carers coming to their house frequently was quite difficult:

Aye, it's [having carers] okay. It's better if you can do it yourself, no doubt. But they're [carers] good. (Patient-3 Male, 73 years old, 3 x hospital visits in 12 months)

I mean, we need them because of… Like you say, we have to have them, otherwise they would never send him out of hospital, if we didn't have care. But sometimes you say, oh, it would be great not to have anybody… We have so many people coming in and out where you think… I know that sounds… It does get, you know… But it's one of those things you can't help. But, like, when my daughter comes, we can sort… We cancel the carers sometimes. But it's quite nice to sort of, you know… Your time is more your own, sort of thing. But we do need carers. We need for them to come in. (Wife of Patient-13, male, 85 years old)

Participants with carers felt that having a good relationship and getting to know a care worker was an enabler to improving the care provided:

They come in - as I've said, they know us, we know them. And... We know each other the full ways. (Patient-13, male, 85 years old)

They've just become friends, really. Because at the moment, it's pretty... It's pretty steady. It goes through a few……but at the moment we seem to be getting more or less the same carers, and they're pretty good. (Wife of Patient-13, male, 85 years old)

It was perceived that lack of consistency of care from carers made life more difficult, including inability to plan a day trip and having to tell unfamiliar carers what to do. Moreover, Patient-10 was particularly displeased when he was sent new carers he never met before and his carer, who was also involved in the interview, felt he was much happier with his care when he had just her and another care worker providing him care:

The way it goes, you can't just, like… Oh, I've got my carer that day. And you're alright, and then you find out, no I haven't got the carer. I've got somebody else. And they could be doing something that day. Like with… You couldn't go forward. You couldn't plan anything. (Patient-10, male, 64 years old)

> *I think the carers are Age Concern. What happens – you've got your regulars. But the one that came today was a complete stranger. They had been once before, with one of the carers, and I had to tell her to do… Empty the bottles, take the cup into the kitchen, get the trolley into the sitting room… (Patient-19, male, 79 years old)*

> *And then they would send people that you've never met before. And you're supposed to meet them. (Patient-10, male, 64 years old)*

> *Oh, well, I mean you were a lot better when it was just us two. Your mood… (Carer of Patient-10, male, 64 years old)*

Some participants described problems that they had experienced with carers. Patient-18 recounted his dissatisfaction with the carers provided by social services, and felt that these carers were inexperienced, and as a result had organised his own local carer, while Patient-10 felt that there was variation in the level of care provided by different carers:

> *They never did nothing. Aye. Young… Young kids to come and make your dinner. 16, 18-year olds. And the potato wasn't cooked, and this wasn't cooked. And a lady came in… I had my breakfast dishes in the sink. She peeled the potatoes, carrots and things and then left the dishes in the sink, and that's what I was left with. (Patient-18, male, 79 years old, 12 x hospital visits prior to interview)*

> *Because some of them [carers] didn't look after your physical health when you're coming in and stuff like that. They used to make a cup of tea or whatever. Some of them just don't care. (Patient-10, male, 64 years old)*

Patient-19 felt that care providers are often understaffed and short of time and that this affected the level of care a carer could provide. Moreover, following on from her experience spending two weeks in a care home, Patient-20 perceived that nurses and carers are underpaid compared to doctors:

> *And then I suppose the firm has got 100 carers. And suddenly they get another 20 people on their books. Sometimes they haven't got enough carers to do it. So they ask a carer who's working from seven until midnight – like, can you go to this new one? (Patient-19, male, 79 years old, 1 x hospital visit prior to interview)*

> *I looked at the nurses and care workers at [care home]. Carefully feeding these old people. Being talking to them so nicely. And I thought, blummin' doctors there, you know. You're getting a fraction of what they get. And they're doing far more. And they would go and sit beside them and hold their hand and say, "How are you feeling today?" I think, you know, give them ten minutes. And they're just young girls. They're just kids, you know. They're just 20s - in their early 20s. So patient. And I thought, you know, you're getting a pittance to what a doctor is getting. And he would come in and swan around and... You know, spouting advice here and advice there and doing nothing practical at all. And yet, those girls - those nurses - hands on, and doing the real work. And getting a pittance compared to what the doctors are getting. (Patient-20, female, 80 years old, 8 x hospital visits prior to interview)*

The granddaughter of Patient-6 felt that having carers was currently sufficient for her grandfather's situation, but perceived that in the future her grandfather would need respite

care. However, conflict of opinion was observed, and Patient-6 described a dislike for staying in respite care:

> *We manage on the whole, but at times it is a struggle to keep him here, which is what he would like. He's happy to go into a home for respite care when it gets too much for everybody and him. When he's not well. We have discussed what would happen if that decision was taken out of our hands - like, for example, if he had a fall and broke his hip or something like that. Or broke a limb. When that becomes more difficult for us to nurse him at home, and look after him at home. (Granddaughter of Patient-6 Male, 96 years old, 12 x hospital visits in prior to interview)*

> *You see, I don't like the homes. They would like me to go and stay in a home, but I don't want to. It's not... It's prison. It is. It's next door to prison. (Patient-6 Male, 96 years old, 12 x hospital visits prior to interview)*

Conclusion

The themes that emerged from this study show the attitudes, perceptions and behaviours that influence avoiding hospitalisation in high risk patients. These data suggest that participants felt that fate and old age contribute to poor health and needing hospitalisation. Generally participants felt that the health care they receive was excellent, and the majority of patients described having trust and confidence in their health care providers, and continuity and consistency was important to patients in both the care they receive from their GP, and for those participants who had carers. However, the benefit of continuity of care may be challenged by patient decision making such as deciding against taking medication, having an operation and going into respite care.

Participants perceived that taking preventative medication, having physical aids such as a walking frame or personal alarm if they fall, physical adaptations within their homes such as an adapted shower or a stair lift, living a healthy lifestyle that includes healthy food and exercise, resting and knowing their limitations were enablers of avoiding an unplanned hospital admission, and highlighting the importance of these to patients, carers and healthcare providers has the potential to help high risk patients avoid hospital. Participants also felt that support networks of families, friends and/or neighbours helped them avoid hospital. Reinforcing support networks from family and friends, especially in the high risk patients that described being most anxious about their health, would be beneficial. However, for those with spouses, the strain on the spouse from the physical and mental demands of being a carer should be considered. The strategies that patients described they use to cope with their health conditions including acceptance, positive reinterpretation and growth, mental disengagement, and focus and venting of emotions are fundamental solutions that improve the attitude of patients to their health, and reinforcing these behavioural approaches may be a simple method to help reduce perceived vulnerability and anxiety, and help avoid an unnecessary unplanned hospital admission.

These findings give insights into the perceptions and attitudes of high risk patients towards their health and the health care they receive, and provide deeper understanding of the behavioural aspects that contribute to high risk patients avoiding unplanned hospital admissions.

Next steps

The findings of this study will be presented at the Society for Academic Primary Care (SAPC) North Conference in November 2017 and an article will be prepared for submission to the British Journal of General Practice.

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