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Defining Chronic Cancer: Patient Experiences and Self-Management Needs

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ABSTRACT

Objective Chronic cancer is poorly defined and strategies for supporting patients during this disease phase are lacking. This research defines chronic cancer, explores patient experiences, and reviews patients' support needs against those described in the 2007 Department of Health Generic Choice Model for Long-term Conditions (DoH-GCM).

Design Semi-structured interviews were audio-recorded, transcribed, and data explored for emergent themes. A-*priori* themes from the DoH-GCM were applied: clinical support; self-care and self-management; supporting independence; psychological support; and social and economic factors.

Results 56 patients >12 months post-diagnosis of advanced cancer were recruited from five clinics at a Yorkshire cancer centre: breast (n=11); renal (n=11); colorectal/gastrointestinal (n=12); gynaecological (n=12); prostate (n=10). Most patients aspired to living *normal* lives. Challenges included frequent and lengthy hospital appointments, long-term symptom control, and uncertainty. Only renal and prostate patients reported routine access to specialist nursing. Uptake of support services was varied and there was generally poor understanding of support pathways for non-medical problems and issues occurring when patients were not receiving active treatment. There was variation in coping strategies and ability of patients to attain a positive outlook on life.

Conclusion For patients to do well in this cancer phase requires good self-management of symptoms plus taking an active role in accessing appropriate services as needed. Care planning at the point of transition to the chronic phase of cancer should focus on evaluating patients' needs, clarifying support pathways, increasing the profile and involvement of community services and organisations, and supporting patients and families develop effective self-management skills.

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INTRODUCTION

In the UK it is estimated that one in ten people over the age of 65 lives with cancer [1]. In 2006 there were over 720000 prevalent cancer patients who were up to five years post-diagnosis [2]. The National Cancer Survivorship Initiative, National Cancer Research Institute and National Institute for Health and Clinical Excellence recognise the importance of research to develop strategies to encourage effective self-management for cancer survivors [3, 4] and to improve care planning and targeted service delivery [5]. However, the definition of survivorship is broad. It encompasses early-stage cancer, individuals who are disease free, individuals living with advanced cancer as a chronic disease and those at end-stage of life. In comparison to 'survivorship' and 'advanced cancer', research focusing on the chronic phase of cancer is scarce. Yet, the need to understand chronic cancer is increasingly becoming recognised [6].

In 2007 the UK Department of Health published best practice guidelines for supporting patients living with long-term conditions: The Generic Choice Model for Long-term Conditions (DoH-GCM) [7]. The guidelines were developed to help commissioners understand the process and range of services needed and to improve and personalise services and support for people with long-term conditions. The guidelines suggest common aspects to chronic disease care and illustrate how a collaborative approach to care planning between patients and health professionals should be used to identify individual patient needs and care options. The model set out in the guidelines acknowledges two key stages for patient choice and care planning, 1) diagnosis and re-assessment, and 2) living with a long-term condition. These guidelines highlight similar issues to those presented in earlier documents [5] but focuses on elements pertinent to *living* with a long-term condition (stage 2): clinical support; self-care and self-management; supporting independence; psychological support; and social and economic factors. In theoretical and evidence based models of chronic illness care [8, 9] there is recognition that patients are their own principal caregivers. Within this role, patients are typically expected to adhere to and manage treatments, monitor symptoms and side-effects, and implement specific lifestyle and behavioural changes that improve disease outcomes [10]. The treatment and management of cancer is complex and the opportunities and expectations for patients to take on self-management will vary by disease and treatment. For many patients, there may be few opportunities to undertake behaviour or lifestyle changes that influence disease outcomes.

The complexity and variability in treatment and management of different cancers may be one reason why cancer is often excluded from chronic illness models, and why there is yet to be a common model for the provision of care for chronic cancer patients. It is clear, however, that effective disease management should be tailored and patient centred [11]. In order to work towards this, the specific needs of those living with chronic cancer need to be understood and service provision planned accordingly. The aim of this study is to improve understanding of chronic cancer from the perspective of patients and their informal carers. We review patients' experiences and examine the extent to which the DoH-GCM provides a model of care that meets the needs of those living with chronic cancer.

METHODS

Participants and procedure

Eligible patients were >12 months post-diagnosis of chronic cancer (Box 1) so they could reflect on a substantial period of time living with chronic disease. Patients were considered ineligible if they exhibited overt psychopathology or serious cognitive dysfunction, which would impede their being able to participate, or if they were deemed too ill by oncology staff. From a large Yorkshire cancer centre, outpatients from five oncology clinics (breast, renal, colorectal/gastrointestinal, gynaecological, and prostate) were invited to participate. From each clinic we aimed to interview at least 10 patients presenting diversity in age, diagnosis, and length of time in chronic phase and recruitment continued until emergent themes were saturated. Clinic lists were screened for eligible patients attending for treatment, review, or follow-up assessments. The researcher provided study information, answered questions, arranged and conducted interviews. Patients wishing to attend with an informal caregiver were encouraged to do so. All interviews were conducted at the cancer centre in a private room, were audio recorded, and lasted an average of 50 (range 13-94) minutes. Local NHS ethical and governance committees approved the particulars of the study. Permission was granted for researchers to screen clinic lists for eligible patients and to discuss study participation with patients following an introduction from a member of the clinic team. All patients provided written informed consent.

Box 1. Defining Chronic Cancer

Currently there is no unified definition of when the chronic phase of cancer begins or ends. Following consultation with oncology specialists and health professionals we put forward a working definition of chronic cancer:

- A diagnosis of active advanced or metastatic cancer that cannot be cured
- Active anti-cancer treatments are available that can lead to symptom control, slow disease progression, or prolong life
- The patient is not considered to be at the end-stage of cancer
- The chronic cancer phase ends when the cancer no longer responds to treatment and there are no treatment options available that are expected to slow disease progression or prolong life. Patients will leave the chronic phase when they are expected to have only months to live.

Interview Schedule

A semi-structured interview schedule was developed to gain insight into patients' experiences of living with chronic cancer. The semi-structured method ensured key topics were covered in all interviews but also allowed patients to focus on issues that were most pertinent to them. The following topics were covered in all interviews:

- Diagnosis and treatment history
- Current treatment and care arrangements
- General experiences of living long-term with cancer:
  - physical wellbeing (side-effect management, physical/domestic needs)
  - psychological wellbeing
  - role in society, family, and social networks
  - work/finances/benefits
  - medical and psychosocial information needs and how they prefer to receive this information
- Interactions with health professionals, support organisations, or services were probed to further explore:
  - access/barriers to services use
  - opinion/attitudes towards services
  - opinion regarding service improvements
- Opportunity to discuss any additional points

Data management and analysis

All interviews were transcribed verbatim and thematically analysed using framework methods [12]. This method was deemed suitable as it permits integration of *a-priori* concepts with emergent themes from primary data.

- *Familiarisation*: Each transcript was read and reviewed. Text was segmented into meaningful units and summarised to enhance familiarisation and determine key points.
- *Developing a thematic framework*: Categories and sub-categories were assigned to each unit of text. This process was data driven but allowed for incorporation of *a-priori* concepts.
- *Coding themes*: Each transcript was coded with the developing thematic framework, which was adjusted when new concepts arose that did not fit the existing framework. This process continued until a stable framework applicable to all interviews was established.
- *Mapping and interpretation*: Each framework category was discussed, associations and meanings within and between categories identified, and the findings interpreted.

RESULTS

Participants

From 150 eligible patients, 125(83%) expressed interest in participating and took study information. Of these, interviews with 56(45%) patients were conducted. The remaining 69 patients (from 125 expressing interest) did not have returning clinic appointments scheduled during the study (July 2010-January 2011). 17 patients attended interviews with an informal caregiver (partner/friend/family member). Table 1 presents demographic and clinical details for participating patients.

Interpreting and extracting meaning from interviews

Interview outcomes described using *a-priori* themes extracted from the DoH-GCM, are presented as headings 1-5. An emergent umbrella theme was added to the model as heading 6. Remaining emergent themes are presented as subheadings to the six headings. Box 2 summarises the resultant thematic framework.

Table 1. Patient demographic and clinical details

	N=56				
	Clinic Group				
	Breast (n=11)	Colorectal/ GI (n=12)	Gynaecological (n=12)	Prostate (n=10)	Renal (n=11)
Female (n)	11	3	12	0	5
Age (years)					
mean	61.2	67	60.67	73	61.64
range	52-73	57-83	50-71	58-84	50-83
Time since advanced diagnosis (months)					
mean	61.3	32.8	27.6	44.8	46.4
range	15-155	13-82	14-70	14-73	15-93
Total time living with cancer (months)					
mean	130.0	41.6	39.8	68.4	56.0
range	34-302	13-84	14-111	22-122	15-123
Currently receiving treatment (n)	9	8	9	9	9
Marital status (n)					
Married / cohabiting	8	10	10	5	11
Widowed	2	0	1	2	0
Divorced / separated	1	0	0	3	0
Single	0	1	1	0	0
Missing data	0	1	0	0	0
Continued education after compulsory school age (n)	4	9	7	7	3
Attended interview with partner or informal caregiver (n)	3	1	5	5	3

GI, gastrointestinal

Table 2. Theme 1: Clinical Services

Participant Description	**Quote**
	Managing frequent and lengthy appointments
#35 Prostate Informal Carer	**Carer**: "...we didn't come to yesterday's [appointment] we tend to treat this visit as the more important one... in the end we sort of made a call as to well this one's more important, he had to have the injection, the other one would have just been a chat and general see for the consultant, so we began to make calls like that, which you don't want to make, but...there's an impact on my job and everything else, it all has to be balanced doesn't it.
#115 Colorectal Patient	"...I do have tons, I mean sometimes I can go a week without an appointment, but then I can go a week with five appointments a week you know... my daughter came with me and we were supposed to be something like 2:00pm, we finally got away and it was 'will you switch the lights out as you go out because you're the last here', you know it was 9:30 at night, and she had to pay the parking for that and it's a hell of an item."
#44 Renal Patient	"It's a lot more efficient than it used to be, but it's not so bad when you're just coming back for like your routine follow ups, but when you've had a scan and you're coming back for your scan results, then you know sitting two hours in the waiting room is... doesn't do you any good!"
	GP relationship and role in care
#56 Prostate Patient and Partner	**Partner**: "We've always felt that it could have been diagnosed sooner but the GP we had at that time..." **Patient**: "He could have pursued it further. I told them about the early symptoms, early stages...however"
#122 Colorectal patient	"I've lost a lot of confidence in them [GPs], I have really, I think they probably do their best, but I've had a lot of bad experiences with it."
#01 Prostate Patient	"if anything happens at home you know full well that your GPs not going to be able to cope with it and it's not worth calling an emergency doctor because he's probably in the same situation"

GP, general practitioner

Box 2. Summary of *a-priori* and emergent themes

A Generic Choice Model for Chronic Cancer Care
1. Clinical services
  Continuity of Care and Treatment Decisions
  Managing frequent and lengthy appointments
  GP relationship and role in care
2. Self-care and self-management
  Symptom experiences
  Symptom management
3. Needs for Independent Living
  Activities of daily living
  Instrumental activities of daily living
4. Work, finances, and benefits
  Work and financial planning
  Benefits and Social Security
5. Psychological experiences
  Uncertainty
  Burdening others
  Psychological support
6. Support pathways
  Attitude towards services
  Signposting
  Timely support

1. Clinical services (Table 2)

Continuity of Care and Treatment Decisions

The majority of patients were complimentary about their care. Patients felt able to ask questions and believed staff would make time for them as needed. All patients conveyed they were supported by their medical team to understand treatment options and make decisions. All patients seemed to have a clear understanding of the severity of their cancer and that the intention of treatment was to manage rather than cure their cancer. It was important for patients to feel that staff involved in their care got to know them. This was associated with patients feeling that staff understood their often complex medical history and engendered confidence in the quality of care provided.

Managing frequent and lengthy appointments

Patients expressed varied opinions about hospital visits. The majority of study patients were receiving treatment; the minority were off-treatment attending hospital for review appointments (Table 1). All patients viewed hospital appointments as important, most found regular appointments reassuring, and some described them as socially enjoyable. Across clinic groups, 10(18%) patients described difficulty with waiting times and frequent hospital visits. Frequent and lengthy hospital visits were particularly difficult for older patients using public or hospital transport; patients travelling long distances; younger patients with caring responsibilities; patients in employment or with informal caregivers in employment.

GP relationship and role in care

GP involvement in care varied by clinic group. Eleven (20%) patients reported GP involvement in cancer care: one (breast) patient received hormone (Zoladex®) injections from her practice nurse; two (breast) patients' GPs prescribed pain medication; three (renal) patients' GPs monitored thyroid function; and five (prostate) patients' GPs carried out regular blood tests and advised on cancer related symptoms/side-effects. The remaining patients reported accessing GP services only for non-cancer issues including flu vaccinations or repeat prescriptions. Across clinic groups, 13(23%) patients described a difficult or lengthy procedure before receiving the cancer diagnosis. Seven of these patients reported losing faith in their GP as a result. Some patients felt that diagnosis delays led directly to them having incurable cancer. Feeling let down during the diagnosis procedure had implications for ongoing relationships with GPs and willingness to use GP services. Independent of the quality of relationship with their GP, many patients believed GP practices had insufficient expertise to provide cancer-related care.

2. Self-care and self-management (Table 3)

Many patients described feeling well for periods of time, such as the beginning, end, or between treatments, or that they had good and bad days throughout. During periods of wellness, patients wanted to lead 'normal lives'; to be physically active and socially engaged. One of the greatest challenges to normality was managing multiple and cyclical symptoms and side-effects.

Symptom experiences

Several patients, not currently receiving treatment, reported that cancer had little impact on them. The majority of patients reported multiple symptoms. Acute symptoms, such as vomiting, diarrhoea, and infection, were frequently reported but described as brief, infrequent episodes that were well-managed, and had little impact on their global wellbeing. Of greater significance were symptoms limiting patients' daily and social activities. Across clinic groups the most common chronic symptoms included fatigue, lack of appetite, sleep disturbance, pain, and emotional difficulty. Chronic symptoms were often linked to loss of role in society (loss of employment or ability to contribute to family/social activities) or loss of enjoyment in day-to-day activities.

Symptom management

All patients seemed aware of procedures for managing acute/serious symptoms during treatment. The acute admissions procedure was generally regarded as straightforward and efficient. Patients appeared reluctant to report chronic symptoms to oncologists, viewing them as known consequences of treatment and a trade-off for extended life. Many patients believed their clinicians were not interested in chronic symptoms. Some patients did not report symptoms as they were concerned their doctor would stop treatment, others did not report pain due to concerns about taking pain medication. Patients accepted it was their role to deal with chronic symptoms but many wanted guidance to improve symptom-management. There was variation across clinic groups in routine access to a Clinical Nurse Specialist (CNS) or advanced nurse practitioner, and this had an impact on patients' knowing where to seek advice, particularly when they were not receiving active treatment.

3. Needs for Independent Living (Table 4)

Activities of daily living and instrumental activities of daily living

Independent living refers to a patient's ability to undertake self-care and perform activities of daily-living (ADL) (e.g., bathing, feeding, transferring) or instrumental ADL (e.g., housework, shopping, managing money). Patients reported their need for support with independent living changed during and between treatments. Most commonly patients reported a need for assistance with physically demanding IADL tasks such as shopping, cleaning, or gardening, and reported receiving support from family/friends or paying privately for assistance with these tasks. Five patients described needing help with mobility or ADL around the home: two lived in supported housing; one received installation of mobility aids in their home; and two described applying for but being refused home assistance. Several barriers to the uptake of social care emerged, including: taboos around showing a need for help or having a social worker; lack of opportunity or confidence raising issues with professionals; difficulty completing paper work; and negative outcomes after applying for social care.

4. Work, finances, and benefits (Table 5)

Work and financial planning

Patients who had retired prior to their cancer diagnosis were least likely to report financial difficulty resulting from cancer. The majority of patients who were employed at the time of diagnosis described at first reducing their working hours, leading to early retirement as the cancer progressed. Those remaining in employment tended to be self-employed or worked flexible reduced hours. Many patients of working age wanted to be in employment but barriers to continuing working centred around being unable to commit to regular work due to fatigue, treatment side-effects, and frequent hospital appointments.

Benefits and Social Security

Approximately half the patients reported receiving one or more state benefits. The majority received disability allowances, such as attendance or employment and support allowance. The pathway to receiving benefits was variable. Some patients received guidance from Macmillan or social security staff, others were helped by family members. Several patients reported difficulty in obtaining benefits advice, found the benefits system confusing, and some reported insensitive treatment by social security staff. The majority of patients not claiming benefits had no desire to claim or had assumed non-entitlement due to being retired or having savings.

5. Psychological experiences (Table 6)

Uncertainty

Patients often described uncertainty as the most difficult aspect of chronic cancer. Patients described difficulty coming to terms with not knowing how long they might live and slowly adjusting to their illness being a long-term condition. Waiting for scan results was cited as a particularly stressful and emotional time, and many described living from one scan to the next. Uncertainty and worrying about the future were often related to sleep disturbance, and uncertainty limited many patients' ability or desire to make future plans. Coping strategies included focusing on day-to-day tasks, having strategies in

Table 3. Theme 2: Self-care and self-management needs

Participant Description	Quote
#30 Renal Patient	"Sometimes it [treatment] makes me feel as though I don't want to do anything. It's difficult saying to an employer I'm not coming in today because I don't feel like doing anything... you miss the involvement of work and things like that...but there's nothing I can do about it, I'm not going to get anybody to employ me now in my condition."
#151 Breast Patient	"This coughing, you know it really gets me down, I've had this for six months and it affects my sleeping...I cough a lot, and it's so irritating and debilitating...I can't commit to anything..."
#103 Colorectal / GI Patient	"It just comes over you like a cloud, it's like somebody's drawn a pair of curtains, it's just there, where you can't explain it, it's like an awful fatigue where it just sweeps over your body and you just can't...couldn't lift a cup, you couldn't hold a book you're that tired... ... if there is anything up with me I tell him [oncologist] and all. I mean it's pointless telling him you're poorly and you've got a headache and you just feel like as though you want to go to bed, I mean he'll know all that already, it's if you have pains or losing weight or all that. So no I'm OK."
#37 Renal Patient	"And it's difficult whether to say something or not, because you think, oh they must think I'm an idiot! I've got this, this, this, this I can't possibly tell them about everything."
#129 Breast Patient	"if it was something that came on suddenly and was you know, having a huge effect on me I think I would probably phone here [hospital] and speak to somebody. Particularly while you're having treatment that's the thing to do isn't it, while you're having chemo, in between times I'd have to think about where I was going to direct myself really."
#71 Gynae Patient	"Yes, I've done it twice I think, I've rung up and I've got an appointment the same day... I rang up and I went straight into ward [acute admissions] and every day I had something done and they put me back on my perch and I'm very grateful"
#151 Breast Patient	"I really need to know how to manage this because my husband works full time, so you know, I'm on my own most of the time and I have to do things, you know, and I don't want to be house bound, I want to go out, I want to lead a normal life...sometimes I get really breathless and when you're on your own that's really frightening and so you know, I would really like to know where to go to actually learn how to manage it."

Table 4. Theme 3: Needs for Independent Living

Participant description	Quote
#129 Breast Patient	"...a nurse said to me would you like to see a social worker? And I sort of said no, because at the time I had a partner and I felt perfectly capable of sort of looking after myself...in retrospect if I'd seen that social worker or whoever they would perhaps have said to me you realise that you're eligible for...but because I chose to say no at the time that was sort of closed off to me"
#116 Breast Patient	"I didn't have a bath or a shower for months, my husband tried to get some help, through social services, and a lady did come and we filled in loads of sheets, but nothing happened."

Table 5. Theme 4: Work, finances, and benefits

Participant description	Quote
	Work and financial planning
#45 Renal Patient	"I was on six months full pay, six months half pay so financially we were OK, but I was a bit concerned as to what would happen after 12 months, whether I would retire, whether I'd get ill health and so the financial issues behind that was a bit of a worry."
	Benefits and Social Security
#115 Colorectal Patient	"I mean I just walk in, come in and get my treatment and I leave. I'm so naive like that, I really am. I would never have dreamed of asking for financial aid, I really wouldn't"
#21 Renal Patient	"She said you'll find that you need this extra money, and she said for journeys to and from hospitals and different places, and I have found that I do need the central heating on a lot more, I feel the cold. So I know that money is there to pay the bills when they come."

Table 6. Theme 5: Psychological experiences

Participant Description	Quote
	Uncertainty
#30 Renal patient	"...you sort of live from one scan to the next and just hope that they haven't grown anymore, but you never know."
#117 Breast	"You're sort of running around like a chicken with no head on trying to get everything organised...you don't know how long you've got, what the procedure is or anything"
#147 Breast	"The thing I find the most terrifying is when I've had a scan and things and we're going to hear the results, once I know it I can perhaps cope with it, it's just going in there"
	Burdening others
#115 Colorectal Patient	"I try to keep it away from the kids as much as possible...they're grown women and can cope with it, but ... I don't want to bother them, they're going to have enough trouble when I do finally go"
#121 Renal Patient	"I don't always tell them [family] how bad things are, they know it can't be cured, they know that, but you know, they'll come and say to me 'how are you today?' 'I'm alright'. Even if I'm not, because I don't like to worry them"
#141 Breast patient	"Dr [oncologist] is lovely and she said 'this is my secretary's number ring her anytime', but you can't do that to a consultant, it's not realistic, I mean she was lovely doing it, but it's not a realistic thing to do."
	Psychological support
#151 Breast patient	"You see I try and manage everything myself. Because it's empowering, you know, cancer takes an awful lot of power away from you, you can't control that, but when you can have control that is so important"
#103 Colorectal Patient	"No, they said that the Macmillan nurses are there and there's these self help groups and all this that and the other, I am not going to sit down and listen to other people going on about what's up with them, you know, it's just not me."

place to cope with physically or emotionally difficult days, and striving to focus on positive aspects of life.

Burdening others

Many patients spoke of concerns about burdening others, and were careful to protect their family, particularly partners or children, from knowing the truth about their emotions or the burden of physical symptoms. Patients also described protecting their oncologists; by not taking up time with unimportant questions, not calling when they were unwell, and holding back when reporting symptoms.

Psychological support

Many patients felt unable to express emotions to loved ones, but few sought professional support. With the exception of gynaecological clinic patients, where a CNS leads a support group for advanced cancer patients, participation in support groups or uptake of psychological services was uncommon. Barriers to uptake of psychological support included social taboos and stereotypes; misconceptions about what different services could provide; and lack of information detailing support available locally to patients' homes.

6. Support pathways

Attitude towards services; signposting; timely support

An umbrella theme emerged highlighting generic barriers to accessing support. Patients had misconceptions about the role of services, confusion about who to approach for support, and difficulty accessing timely support. For example, most patients were aware that organisations, such as Macmillan, were available to cancer patients but many believed these services were for end-of-life care or "if things got desperate". Where patients had a need or had received support for psychological, social, or economic needs, the pathway to receiving this support appeared unsystematic. Some patients described being offered support at the wrong time for them, such as during an acute admission and that when future needs occurred they did not know where to turn for support. Support offered by specialist nurses was highly valued, both for specialist medical advice as well as signposting to support services. Those reporting regular access to a CNS appeared to cope better than those without.

DISCUSSION

In this research we put forward a working definition of chronic cancer and encourage further debate to refine this definition. The DoH-GCM is an intentionally broad model focusing on supporting patients to lead independent and productive lives during chronic illness. Categorising patient narratives within this model was straightforward. Combining emergent themes with DoH-GCM provided a more comprehensive framework (Box 2) that highlighted specific problem areas for chronic cancer patients, including: variable treatment schedules and hospital appointments; variable integration between hospital and GP/community services; multiple and changing symptoms alongside the cyclical nature of chronic cancer; and dealing with uncertainty. We identified areas of good clinical practice and areas where improvements in personalised care planning might have the potential to improve self-management and wellbeing.

For chronic cancer, treatment decisions are made to balance disease progression, disease symptoms, and treatment side-effects. Decisions are frequently based on quality-of-life considerations through discussion of symptoms and performance of I/ADL. Patients in this study described good communication with oncology specialists and appeared well supported to understand their illness and participate in treatment decisions. Whilst there appeared to be good support mechanisms for managing acute symptoms, particularly during treatment, we identified a culture of patients under-reporting chronic symptoms, corroborating similar findings in the literature [13]. The extent to which under-reporting is intentional by patients wishing to ensure eligibility for treatment, or unintentional through misunderstanding of what is medically significant, is yet to be determined for this population.

It is clear that chronic symptoms can reduce quality-of-life [13]. Patients in this study linked chronic symptoms to loss of employment, inability to contribute to family or social activities, and a loss of enjoyment in day-to-day activities. These issues can be broadly categorised as ‘psychosocial’, and there is typically good provision for professional support in these areas across tertiary/secondary and primary care. In this study less than half the patients reported routine access to a CNS (advanced nurse practitioner or key-worker); a finding reflected in other studies with advanced cancer patients [14]. We identified differences between patients who did and did not report routine access to a CNS in their knowledge of care pathways (where and how they could obtain support) for different problems. Patients with CNS support described how the nurse provided regular opportunities to discuss problems, supported symptom management, and facilitated access to services. For those without CNS support, there was variability in symptom-management, confusion regarding who they should talk to about different problems, and unsystematic access to support services. These findings concur with previous work showing that patients with cancer are most likely to have unmet needs for psychological concerns, social support, and independent living [15, 16].

Patients’ need for support should be considered within the context of the duration of chronic cancer. Patients in this study were on average 42 months (3.5 years) post-diagnosis of chronic cancer (range 13-155 months/1-13 years), and had been receiving treatment and attending hospital appointments throughout. Symptom control and psychosocial issues can occur at any time in the chronic phase and the need for support will vary over time [17]. Evaluation of needs and support planning must consider the cyclical nature of chronic cancer care. A route for patients to access timely support for medical as well as non-medical issues when they are not receiving treatment must be provided. In the current model of cancer care, with increasing focus on acute needs, it may be necessary to look beyond the acute treatment setting in providing this long-term service.

The DoH-GCM [7] advocates patient choice. A model of integrated care between cancer centres and community services may benefit some chronic cancer patients, particularly those without routine access to a CNS, or those living remote to cancer centres. The integration of primary care services at the point of diagnosis with chronic cancer may have the potential to improve access to support, may improve management of chronic symptoms, and may facilitate the transition to end of life care. Research is needed to establish best methods for assessing patients’ requirements for support during chronic cancer and ensuring that assessment outcomes correspond to efficient and targeted access to support. Research is also needed to determine whether or not patients are more likely to report accurate symptoms to practitioners who do not control anti-cancer prescriptions.

We found evidence of successfully integrated service provision for several patients from breast, renal, and prostate clinics, for whom aspects of cancer care were routinely provided for by GPs/practice nurses. For the remainder of patients, the cancer centre was the only resource for cancer-related problems, with GP services providing solely for non-cancer issues. We identified several barriers to the use of primary care services. In this study 23% patients reported a difficult diagnosis procedure with 13% losing trust in their GP service as a result. Many patients perceived their GP practice lacked expertise to support them, a finding reflected in previous research by both patients [18] and GPs [19]. With the development of national initiatives such as the National Service Frameworks [20] and registries of practitioners with specialist interests in cancer, it may become easier to plan integrated care based on the availability of specialist services local to patients' homes. This research highlights the importance of cancer specialists acknowledging and discussing diagnosis experiences, GP relationships, and patient expectations if primary care services are to be integrated into this stage of cancer care.

This report documents the personal experiences of a small sample of patients attending a specialist cancer centre. The generalisability of these experiences to the wider chronic cancer population needs to be explored in future work. For example, the eligibility criteria of >12 months post chronic disease excluded early chronic cancer patients, and voluntary participation in this study may have excluded patients with poorer health or those in the late stages of chronic cancer transitioning to end of life care. Our current programme of research continues to explore chronic cancer. We have conducted interviews with staff who provide care and services for chronic cancer populations and hope to identify specific challenges to service organisation and delivery for this patient group. We have also developed a survey, based on the narratives of patients in this study. We are currently administering the survey to patients across several hospitals in the Yorkshire Network aiming to determine whether the experiences documented in this report are generalisable to a wider population of patients. We hope that this ongoing research will help to answer some of the questions that remain about the care, support, and service needs of this patient group.

CONCLUSIONS

Care planning at the point of transition to chronic cancer should focus on evaluating patients' symptoms and need for psychological, social, and economic support. Re-evaluation of chronic symptoms and psychosocial problems should be planned with patients at regular intervals throughout the chronic phase, including treatment-free periods. Where problems are identified these should be followed-up with information showing how different service providers can meet patients' needs, and consideration of patients' ability to undertake self-management. Wherever possible, support care planning should review availability of services local to patients' homes, and consider whether alternative support pathways are required for treatment-free periods.

REFERENCES

1. King's College London, Macmillan Cancer Support and National Cancer Intelligence Network, 2008.
2. http://info.cancerresearchuk.org/cancerstats/incidence/prevalence/?a=5441. [Accessed december 2011];
3. NHS Improvement: Adult Cancer Survivorship Initiative. Living With and Beyond Cancer: The improvement story so far. 2010.
4. Foster C, Brown J, Killen M*, et al.* The NCRI cancer experiences collaborative: Defining self management. *Eur J Oncol Nurs* 2007;**11**:295-7.
5. NICE. Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. London: National Institute for Clinical Excellence; 2004.
6. Berlinger N, Gusmano M. Cancer chronicity: new research and policy challenges. *J Health Serv Res Policy* 2011;**16**:121-3.
7. Team DoHCP. Generic choice model for long term conditions. In: Health Do, editor. London: Department of Health; 2007.
8. Leventhal H, Nerenz DR, Steele DJ. Illness representations and coping with health threats. Baum A, Taylor SE, Singer JE, editors. Hillsdale, NJ: Erlbaum; 1984.

9. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Eff Clin Pract* 1998;**1**:2-4.
10. Bodenheimer T, Lorig K, Holman H*, et al.* Patient self-management of chronic disease in primary care. *JAMA* 2002;**288**:2469-75.
11. Holmström I, Röing M. The relation between patient-centeredness and patient empowerment: A discussion on concepts. *Patient Educ Couns* 2010;**79**:167-72.
12. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. Bryman A, Burgess R, editors. London: Routledge; 1994.
13. Mock V, Atkinson A, Barsevick AM*, et al.* Cancer-related fatigue. Clinical Practice Guidelines in Oncology. *Journal of the National Comprehensive Cancer Network : JNCCN* 2007;**5**:1054-78.
14. Aranda S, Schofield P, Weih L*, et al.* Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *Eur J Cancer Care (Engl)* 2005;**14**:211-22.
15. Soothill K, Morris SM, Thomas C*, et al.* The universal, situational, and personal needs of cancer patients and their main carers. *Eur J Oncol Nurs* 2003;**7**:5-13.
16. Sanson-Fisher R, Girgis A, Boyes A*, et al.* The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000;**88**:226-37.
17. Frost MH, Suman VJ, Rummans TA*, et al.* Physical, psychological and social well-being of women with breast cancer: The influence of disease phase. *Psycho-Oncol* 2000;**9**:221-31.
18. van der Kam WJ, Branger PJ, van Bemmel JH*, et al.* Communication between physicians and with patients suffering from breast cancer. *Fam Pract* 1998;**15**:415-9.
19. Tanner G, Myers P. Secondary–primary care communication: impressions of the quality of consultant communication with specific regard to cancer patients. *Primary Health Care Research and Development* 2002;**3**:23-38.
20. National Service Frameworks: a practical aid to implementation in primary care. Department of Health, 2002.