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"*What's fair to an individual is not always fair to a population*": A qualitative study of patients and their health professionals using the Cancer Drugs Fund

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ABSTRACT

Objective: To understand the values attached to cancer treatment at the end of life (EoL) to inform policy decisions around the Cancer Drugs Fund (CDF) and the National Institute for Health and Care Excellence (NICE) EoL criterion.

Design: Semi-structured interviews with patients and health professionals.

Purposive recruitment was performed iteratively alongside analysis of interview transcripts using constant comparison.

Participants: Patients with incurable prostate and colorectal cancer (n = 22) who received drugs funded through the CDF and oncologists and palliative care professionals (n = 16) treating patients on CDF drugs.

Results: While the majority of patient and oncologist participants expressed gratitude for access to the CDF, some patient participants reported experiencing a sense of guilt, and many oncologists admitted to concern about the justice of a ring-fenced fund solely for anti-cancer drugs. For patient and professional participants, cancer drugs were not necessarily seen as a funding priority over other calls on the NHS purse. Overall, patients and health professionals emphasised prioritising quality over quantity at the end of life, with only a minority describing improved quality of life at the end of life which added value.

Conclusion: While patients and oncologists appreciated the drugs available through the CDF, most expressed concern about its fairness. Competing participant views about the added value of the end of life is challenging for resource allocation.

1. Introduction

Between 2000 and 2018, 305 anti-cancer drug decisions were published by the National Institute for Health and Care Excellence (NICE) which, based on the drugs' clinical and cost-effectiveness, recommended (or not) their use in the National Health Service (NHS) in England and Wales [1]. NICE assesses the value of a technology using a cost utility approach (cost per quality adjusted life year [QALY]) and combines this finding with social value judgements, identified by the NICE Citizens Council (established in 2002) [2,3], In 2009, NICE introduced a specific end of life (EoL) criterion: that drugs used to extend life (by three months or more) in the last two years of life (in small patient populations) could be increased (in practice up to £50,000 per QALY) [4]. This is compared with the usual cost-effective threshold applied to other technologies of £20-£30,000 per year of quality life year gained [5]. All 66 NICE recommendations which cite the EoL criterion are for cancerous or precancerous conditions [6]. The EoL criterion has been cited as a "positive access driver for treatments", specifically for those drugs lacking phase 3 data required for other drug approvals [7]. In other words, the current use of the EoL criterion exclusively for anti-cancer drugs and the potentially lower evidence threshold required for the EoL criterion are two ways in which anti-cancer drugs arguably receive 'special treatment' compared with other pharmaceuticals and other health technologies.

A subsequent policy endeavour in England that facilitated access to anti-cancer drugs at the end of life was the Cancer Drugs Fund (CDF). The CDF was established in 2010 as a ring-fenced fund for cancer pharmaceuticals which NICE had either not recommended

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due to poor cost effectiveness or had not evaluated. In reality, the CDF provided access to drugs for patients with incurable cancer, where treatment was too costly even within the extended NICE threshold for the EoL criterion [8]. The CDF consistently overspent despite receiving an annually increasing budget, additional top-up funds and introducing prioritisation criteria to rationalise funded treatments. In 2016 responsibility for anti-cancer drug funding decision making returned to NICE, overturning the independence it had enjoyed as a ring-fenced fund under the oversight of NHS England.

The six-year CDF policy experiment has since been discredited by a number of sources. It has been criticised for delivering poor value for tax payers through a net health loss for the population, both as a result of the lost opportunity of this money for spending in other areas of the NHS, and for failing to fund drugs which represented 'meaningful clinical benefit' according to validated international scales [9]. It also provided scant evidence to advance understanding of the use of high-cost anti-cancer drugs in incurable cancer [10]. Even now that the CDF is under the NICE umbrella for decision making, it faces persistent criticism that its current form permits drugs with a lower threshold of evidence to enter the market compared with the processes established for drugs for other diseases [11]. Whether these different policy approaches for anti-cancer drugs reflect actual public priorities for added value of life at the end of life, added value for cancer treatments, or neither, is unclear, [12–19]. The largest systematic review investigating the value attributed to cancer by the public found no 'consistent support' for greater value for health gains in patients with cancer (compared with patients without cancer) [20]. Others studies have found little evidence of support for giving priority to end of life treatments [19]. Valuing anti-cancer drugs at the end of life above other drugs in the NHS, during the time of the CDF's operation as an autonomous ring-fenced fund, but prior to its transition into a managed access fund is explored in this manuscript. This study uses semi-structured interviews to investigate professional and patient views about funding for cancer care and whether cancer and the end of life should have greater value in funding compared with other diseases.

2. Methods

2.1. Design

Face-to-face audio-recorded semi-structured interviews were undertaken with patients with incurable colorectal and prostate cancer, and oncology and palliative care consultants in the South-West region of England. This study is reported in line with the consolidated criteria for reporting qualitative studies (COREQ) [21] and was approved by the SW Ethics committee in 2013 (REC reference 13/SW/0007).

2.2. Sampling and recruitment

Purposive sampling was employed to recruit patients with prostate and colorectal cancer who were taking drugs prescribed on the CDF. Prostate cancer is a common cancer and specific prostate cancer treatments were listed in the top five most commonly prescribed drugs on the CDF at the time of interview [22]. Patients with colorectal cancer were recruited as a comparative case study due to differences in the treatment regime (intravenous as opposed to oral) as well as an opportunity to compare gender perspectives. Colorectal cancer accounted for two of the five most commonly prescribed anti-cancer agents on the CDF in this period.

Oncologists were sampled as the main professional group referring patients on a case-by-case basis for life-extending anti-cancer drug therapy on the CDF. Palliative care consultants are involved in Multi-Disciplinary Team Meetings (MDT) decisions about the eligibility of a patient for drugs available through the CDF. A number of patients seen by palliative care will have accessed drugs through the CDF. Palliative care specialism in care of patients at the end of life means they have a unique perspective on the value of life at the end of life.

Patients were purposively sampled from one teaching and one district general hospital and health professionals from three district and one teaching hospital in one region of England. Eligible patients (i.e. those receiving CDF drugs for prostate or colorectal cancer) were identified by clinicians at out-patient clinics (and one patient through the chemotherapy day unit). Sampling was done in a stepwise fashion: data gathering, followed by data analysis, followed by more data gathering [23]. Once no new data themes were emerging from the patients with prostate cancer from a teaching hospital setting, a comparator group of patients with prostate cancer were purposively recruited from a district general hospital setting, along with patients with colorectal cancer as comparative groups.

Professional participants were identified by checking hospital websites and cross-checking specialty information with the switchboard at each trust. Invitations to participate were sent by email and letter, to all oncologists (colorectal and urological subspecialties) and all palliative care consultants. A single reminder was sent after approximately one month of no response.

2.3. Data generation

Interviews took place between April 1st 2013 and December 1st 2014 at patients' homes (20/22), at the hospital following an out-patient appointment (one) or at the university (one). Patient participant interviews most commonly took place with a spouse or other family member present (17/22). Professional interviews were conducted over the same period in the participants' place of work (hospice or hospital 15/16) or the consultant's home (1/16). Unobtrusive digital audio-recording was used for all interviews. The same researcher (CC) conducted all interviews and audio-recorded reflective field notes. The topic guide was generated in consultation with two experienced qualitative researchers and the PPI representative (AOS, JD, CH) and then adjusted on three separate occasions to probe emerging themes more effectively.

For some questions, an explanation of the CDF or the NICE EoL criterion was required before the participant could discuss their understanding of the value of the organisation or criteria. These explanations were short, generic, and prepared in advance with co-author consultation to avoid undue influence on the data collected.

All participants in this study received written information before agreeing to participate and provided written consent before recording commenced. No participants declined being recorded. All audio-recordings were transcribed verbatim, using standard notation, by the same experienced transcriber. Transcripts were read in conjunction with audio-recordings to ensure quality of transcription (CC). Participant checking of the transcripts or of the findings was not undertaken due to the emotional nature of the interviews for patients and time pressures of professional participants.

2.4. Analysis

Analysis was based on a grounded theory approach with inductive generation of hypotheses [24]. Line by line coding of the transcribed data identified key themes [23]. Coding structures were recorded in NVivo software. Of the 38 interviews read and coded by CC, eight (21%) were read and coded independently by supervisors (JD, AOS) to assess consistency in coding and emergent themes. Coding discrepancies were discussed, and agreement reached. Themes were compared with each other and with older and newer

Table 1
Patient participants.

ID (n = 22)	Age range	Sex	Site	Cancer Type	Cancer diagnosis (years)	Prior chemo-therapy	Drug and duration (weeks)
Mr X	70-75	M	TH	Prostate	15	Y	Enzalutamide: 40
Mr P	65-70	M	TH	Prostate	13	Y	Enzalutamide: 4
Mr D	60-65	M	TH	Prostate	11	N	Abiraterone: UD Enzalutamide: 6
Mr Y	80-85	M	TH	Prostate	10	N	Abiraterone: 12
Mr N	70-75	M	TH	Prostate	10	Y	Radium 223: 3rd cycle
Mr A	80-85	M	DGH	Prostate	10	N	Abiraterone: 52
Mr M	75-80	M	TH	Prostate	6	N	Abiraterone: UD
Mr T	70-75	M	TH	Prostate	6	N	Abiraterone: 16
Mr Q	65-70	M	TH	Prostate	5	N	Enzalutamide-Bicalutamide trial (blinded): 81 Abiraterone: 20
Mr O	85-90	M	TH	Prostate	4	N	Abiraterone: 6
Mr I	70-75	M	DGH	Prostate	4	Y	Enzalutamide: 51
Mr J	55-60	M	DGH	Prostate	4	Y	Radium 223: 1st cycle
Mr R	70-75	M	DGH	Prostate	3	Y	Enzalutamide: 12 Cabazitaxel: 10 cycles
Mr S	70-75	M	TH	Prostate	3	Y	Enzalutamide: 8
Mr V	65-70	M	DGH	Prostate	2.8	Y	Enzalutamide: 12
Mr K	70-75	M	DGH	Prostate	2	Y	Enzalutamide: 6
Mr C	75-80	M	DGH	Prostate	2	Y	Enzalutamide: 3
Mr F	65-70	M	DGH	Prostate	1.9	N	Enzalutamide: 1
Mr U	80-85	M	TH	Prostate	1.5	N	Abiraterone: 4
Mrs L	50-55	F	DGH	Colorectal	4	Y- ongoing	Cetuximab: 24
Mr E	70-75	M	TH	Colorectal	3	Y- ongoing	Bevacizumab: 20 soon to start Cetuximab
Mrs B	50-55	F	DGH	Colorectal	2	Y- ongoing	Cetuximab: 12 cycles Bevacizumab: 4

UD: Undisclosed duration, TH: Teaching hospital, DGH: District general hospital.

data, identifying dissonant views and defining higher theoretical categories. Data analysis was iterative, using the technique of constant comparison to define and refine emergent themes. Data counts have been predominantly represented with words, for instance, 'several', 'the majority' in keeping with the narrative style of the results. However, some numerical counts have been included where this adds meaning. Reflexivity: data collection and analysis should be viewed in the context of a female, health professional with experience in public health and palliative medicine.

3. Results

Patient (Table 1) and professional (Table 2) participant characteristics.

3.1. Patient participant characteristics

Twenty-one patients with prostate cancer agreed to interview: 19 of whom were interviewed (one was not interviewed due to deteriorating health and another due to loss of contact). Ages ranged from 59 to 85 years (typical for this cancer type) with interviews between 31 min and one hour and 47 min.

Seven patients with colorectal cancer agreed to interview, however only three patients were able to participate (two withdrew due to ill health and two did not respond after initial agreement). Ages ranged from 54 to 71 years. Interview duration ranged from 41 min to one hour 18 min.

3.2. Health professional participant characteristics

21 health professionals responded to the study invitation, but five responders were not interviewed due to: moved out of area (one); wrong sub-specialty recorded (one); failure to respond to subsequent contact (one); time pressures (one); and feeling they would have nothing to contribute (one). Sixteen health professional interviews were conducted ranging from 31 min to one hour six minutes.

3.3. Emergent themes

Three major themes were identified in the data and these are now described in more detail with the use of patient participant and health professional participant quotes.

3.3.1. Resource allocation in the NHS

Patient participants expressed gratitude for having access to the CDF. Three patient participants acknowledged from the start of the interview that the NHS had to make tough choices due to its limited resource in a context of increasing demand. However, patient views diverged amongst those participants who accepted that some treatments were not affordable on the NHS and those who believed that human life was too valuable to ration in *any way*.

> *"There's always going to be this tension between what's available and what we can afford. . .I realise that there are limits, you know. . . .Oh well I've got it, blow everyone else, but it's not like that, is it?"*
> *[Mr X, 74 years old, 15 years with prostate cancer]*
> *"We've paid all our working lives (pause), you know, definitely there should be the budget there. . ."*
> *[Mrs B, 55 years old, two years with colorectal cancer]*

On the other hand, professional participants universally accepted that rationing takes place, but generally described resource allocation decision making as "too difficult" for them (four palliative care consultants, two oncologists). Therefore, when asked to describe priorities for the £200 million allocated to the Cancer Drugs Fund (at the time of interview), many were reluctant to comment. Interviewees struggled to reconcile the 'patient in front of them' with population justice and resource allocation decisions for patients with terminal cancer.

Table 2
Health professional participants.

ID (n = 16)	Speciality	Years a consultant> or ≤ 10 years	Sex	Practice setting*
Dr M	OncColo	≤	F	DGH
Dr H	OncColo	≤	F	DGH
Dr Y	OncColo	>	M	DGH
Dr X	OncColo	>	F	DGH
Dr A	OncColo	>	M	TH
Dr C	OncColo	>	F	TH
Dr D	OncUrol	>	M	TH
Dr B	OncUrol	≤	F	TH
Dr I	OncUrol	≤	F	DGH
Dr G	OncUrol	>	F	DGH
Dr E	Palliative	≤	F	TH
Dr Z	Palliative	>	F	TH
Dr L	Palliative	≤	F	TH
Dr Q	Palliative	>	F	Community
Dr P	Palliative	≤	F	Community
Dr O	Palliative	>	F	DGH

* These denote the most common practice settings, although some palliative care and oncology professionals practiced across more than one site (e.g. DGH and TH or community and DGH).

". . . what's fair to an individual is not always fair to a population. . .."
[Dr B, urological oncologist]
"I try not to think about it too much because I'm not clever enough to work out how you fund everything within the NHS with the drugs and the budgets that you have available. . .I just concentrate on my patients who I see benefits for."
[Dr I, urological oncologist]

3.3.1.1. Unacknowledged preference for cancer?. Patient participants recognised a cultural anxiety around cancer meaning that it was promoted above other diseases, influencing greater demand for political action and treatment. The fear of cancer's insidious onset and the sense it was unavoidable or random, with limited treatment options, was felt to influence funding decision making.

". . ..Cancer's something you fall foul of which heart disease, fair enough it can be hereditary but by and large it's done through your own fault. . ."
[Mr N, 73 years old, ten years with prostate cancer]

However, despite this acknowledgment, the majority [15] of patient participants did not feel that cancer warranted prioritisation in resource allocation decision making.

". . .somebody that's got a heart problem obviously they probably think the same way as I do. They're frightened to death and if they can't get something from the funding then it's like well you're playing with my life. . ."
[Mrs L, 54 years old, four years with colorectal cancer]

Although most clinician participants described a sense of inequity around the prioritisation of cancer above other diseases, some explained potential reasons for its extra investment being a reflection of public values and the 'emotive' nature of cancer (two oncologists, three palliative care); the influence of the media (two oncologists, two palliative care); an expression of the historic under-funding of anti-cancer drugs (two oncologists); a representation of the significant burden it presents in terms of morbidity and mortality (two oncologists), or perhaps just 'politics'(four oncology, one palliative medicine).

"if there's two boxes for collection and one says COPD and the others says cancer, people will give to the cancer, um, because its very emotive, isn't it, but more people die without cancer than with cancer but the funding is very skewed."
[Dr Q, consultant in palliative medicine]

3.3.2. The trade-off between individual and population justice: the perceived strengths and weaknesses of the CDF

Despite all patient participants' treatments having been funded by the CDF, only eight of the 22 (36%) had any knowledge of its existence. Seven participants recalled a conversation with their consultant and one had heard about it through the media. However, several patient participants (3/22) expressed guilt in their use of the high cost drugs through the CDF, feeling it was 'selfish'. Two other participants described the potential that they may be accused of being 'selfish' but that they deserved the drugs ("I'm worth it").

"Well, that [the CDF is ring-fenced money for cancer] could make one feel selfish. Oh I'm alright Jack, but what about the people coming along. . .I would like to think that it was available for everybody."
[Mr O, 85 years old, four years with prostate cancer]

Health professionals were all familiar with the CDF and articulated a similar conflict to patients in its use. Concern around the CDF and its use was expressed in two ways: firstly, two oncology participants commented on the guilt they had felt in the past as a result of the 'postcode lottery' in prescribing or the inequality of access between private and NHS care- a guilt that had been improved with the CDF. Conversely, the majority expressed significant concern about access to the CDF in its current form, due to a sense it was a poor use of resource for the population.

"I don't think it is fair necessarily [the CDF] . . ."
[Dr L, Palliative care consultant]

Health professional participants clearly articulated both strengths and weaknesses of the CDF. The general strengths of the CDF being: greater access to anti-cancer drugs; potential responsiveness to the needs of rare cancers and reduced clinical practice variation. However, professional participants also criticised the CDF for its potential to undermine and duplicate NICE processes, reducing clinical discretion in prescribing. The most frequent arguments expressed against the CDF included its effect on the generation of evidence. Three oncologists and two palliative care participants were disappointed that the CDF did not provide a greater evidence base towards improving care for patients in the future. Not only was there a criticism of the usefulness of the data for informing better cancer care in the future, but two oncologists felt there was a danger that the introduction of the CDF may reduce the drive to perform clinical trials and therefore, further reduce the quality of evidence to improve care in the future for the population.

Table 3
The trade-off between individual and population justice: the perceived strengths and weaknesses of the CDF.

"Whereas before the [CDF] there was a huge discrepancy between private and NHS. . .[after] that really changed." *[Dr C, colorectal oncologist]*
". . .People with very unusual diseases who needed very high cost drugs. . .for that group [care] has been revolutionised by the Cancer Drugs Fund. . ." *[Dr A, colorectal oncologist]*
"The downside has been that it's [the CDF] completely neutered NICE. . ." *[Dr A, colorectal oncologist]*
". . .with the CDF becoming so prescriptive, the CDF has started to dictate practice. . ." *[Dr H, colorectal oncologist]*
"I suspect that people would feel happier if we had some process where we actively recorded what happened to these patients [on the CDF] because. . .nobody really is following up what's happening. . ." *[Dr G, urological oncologist]*

Table 4
Value at the end of life.

"Well I find it [EoL criterion] quite controversial. . .because at the end of the day, as I've just said, it's not so much about extending life, it's the quality of life. There's no point someone saying well you can live for two years but life's going to be a living hell. . ." *[Mr I, 72 years old, four years with prostate cancer]*
"it's a nonsense that you would give more value to something that is going to extend a life by two weeks than you would give to something that might improve a quality of life. . .for twenty years. . .you might say, but if you're dying, two weeks. . .[is]priceless. It's not. It's only priceless if you use that two weeks to put your affairs in order. . . but. . .because they will be having those extra two weeks on a cancer drug, they're not going to use it to write a will, etcetera. . . I think cancer drugs add to the whole kind of death denial. . ." *[Dr E, palliative care consultant]*
". . .It may sound clichéd but life has a different intensity when you know. . .your inevitable demise and roughly when that might be. . .each day now. . .is more important to me than a day six years ago [pre-diagnosis]. . . knowing that, it becomes a more intense way of living, I see the value in it. . . [I] support that [EoL criterion]." *[Mr Q, 65 years old, five years with prostate cancer]*
". . .I build things in Meccano on a construction of systems. . .there may come a point where I can't do [cycling] but I may still be able to have manipulative skills. . .I've stacked up lots of films I've always wanted to see and I've got them on DVD so when I'm a bit more gaga. . . so I'm sort of metering these things out as to what I'll do as the situation demands." *[Mr Q, 65 years old, five years with prostate cancer]*

(Table 3: Participant quotes on the strengths and weaknesses of the CDF).

3.3.3. Value at the end of life

Debates over whether life 'at the end of life' (as defined by NICE) is more valuable than life before a diagnosis of terminal cancer led to most patient and professional participants emphasising that value at the end of life was determined by the quality of that life. However, one patient, who described being in severe pain with his cancer, felt motivated by the opportunity to be alive longer with his family despite describing his life as poor quality. While the pre-eminence of maintaining quality of life rather than quantity was almost universal amongst all participants, there was considerable debate over the evolving nature of quality of life, where participants adapt to changing expectations of physical function, for instance. (Table 4 Value at the end of life participant quotes)

3.3.3.1. The value of the end of life for a population. There are important population implications arising from valuing the end of life higher than other times of life. For instance, having a more accessible NICE threshold for expensive drugs through the EoL criterion has an opportunity cost attached for other health spend. Most interviewed palliative care and oncology consultants described generally poorer quality of life at the end of life. Therefore, prioritising that time- over other times, was considered poor value for the individual, but also for society, where the money could have been spent supporting patients to access treatments that provided quality of life before they became so unwell at the end of life.

> *". . .if you can keep a patient. . . in their sixties, working and having a normal life with metastatic disease, isn't that more valuable to society than waiting until they're within two years of death [to prioritise their treatment]."*
> *[Dr I, urological oncologist]*

There was also a pragmatic concern raised by participants (one patient and several professional participants) around the feasibility of valuing time at the end of life compared with other times in life, when identifying the end of life prospectively was not easy. Participants expressed concern at how the uncertainty of identifying time at the end of life in medical practice could translate into policies that were challenging to fairly enforce.

3.3.3.2. The dissonance. Three oncologists and two palliative care physicians disagreed with the majority of clinicians, feeling that time at the end of life may have added value for some individuals, despite any personal costs in terms of added time spent in hospital and potential treatment side effects and complications. Many clinicians recognised that for patients, all life, and in particular their last months of life, has immeasurable worth to the individual and their family and therefore there was a dissonance between their thinking about the individual patient and the NHS population with cancer as a whole. Of those participants describing this apparent conflict between the value of time at the end of life for the population and for the individual, one palliative care participant and one oncology participant cited examples of young patients or young families having greater value at the end of life, therefore there may be a conscious or subconscious context to the clinician responses where individuals at the end of life in this context (young) may be perceived to have added value.

> *". . .[a] very expensive treatment [with]. . .life prolongation of six to eight weeks. . .doesn't seem to be a good use of money, but if you said that to me when I had somebody in front of me who had young children I would probably feel very, very differently"*
> *[Dr O, palliative care consultant]*

4. Discussion

Patient participants shared a sensation of concern or guilt around being treated differently through the CDF. Oncologists expressed concern at their personal conflict between appreciating access to anti-cancer drugs through the CDF, while admitting this may be unfair for the population. Oncology and palliative care consultants shared common ground in finding resource allocation decision making challenging (15/16) and the vast majority concurred that the value of life at the end of life was no greater than at other times of life: value was determined by quality. However, defining the changing quality of life in incurable cancer was seen as complex and several participating clinicians admitted to feeling time at the end of life, for some individuals, may have greater importance. Several patient participants also felt strongly that the end of life had greater value compared with other times of life, in spite of their increased physical limitations. Therefore, there were differing views amongst professionals and amongst patients around the value of time at the end of life.

4.1. Comparison with the literature

These interviews reinforced the finding that health professionals were uncomfortable practicing prioritisation decision making

[25]. There is no literature specifically around the perceptions of the CDF and its role in funding anti-cancer drugs at the end of life in the UK for patients or professionals with which to compare our findings. However, comparison has been made here with the literature around the value of cancer prioritisation and the value of the end of life separately. In 2017 a systematic review concluded that there was "no consistent support for a preference for health gains to cancer patients" [20]. This was also articulated by the vast majority of professional and patient participants in this work. A cross-European study in 2014 described five predominant narratives in the prioritisation debate, of which three were articulated by our study participants. Themes of the value of all life ("the intrinsic value of life") and the preeminence of quality of life ("Quality of life is more important than simply staying alive"), as well as the importance of population justice ("Egalitarianism and equality of access") emerged from a number of our professional and patient interviews. Other emergent themes in the cross-European study which were not specifically probed in our interviews included "fair innings" and "severity" [26].

Findings from empirical research about the value of the end of life demonstrate significant heterogeneity and vary according to the population sampled and the methodology used [12–19,26]. However, the conflicting views presented in the literature were all described by participants in a single, well-conducted study by McHugh et al, who summarized the divergent views as follows:

1) all life-extending treatments should be made available

2) there is a trade-off between making effective treatment available and understanding that there is finite resource, where social value judgements should be considered

or 3) a combination of 1 and 2 which emphasizes the role of quality of life [14].

Interviews with patients and professionals in this study reiterated these divergent views. Professional participants in our study described the importance of both social value judgements and quality of life in prioritisation decision making and a small number of patients expressed a belief that all life-extending treatments should be made available.

Integrating themes around the value of the end of life with themes for the value of cancer prioritisation in decision making is relevant in the policy context of the CDF and the NICE EoL criterion. The literature findings in both domains share themes around the value of quality of life (although how to measure it is not clear) and the importance of considering social value judgements (such as equity) in all prioritisation decisions whether for end of life or cancer. Participants in this study shared similarly diverse viewpoints as found in the literature, with the majority reinforcing findings around the value of quality of life over quantity and the value of equity over the preeminence of any disease type per se. The views of a smaller number of participants – both health professionals and patients - who noted the less commonly held view that there may be quality in life which has equivalent or greater importance, despite physical limitations, at the end of life need to be considered in population decision making.

4.2. Strengths and limitations of the work

This study was limited by being focused on only two cancer types and primarily prostate cancer, and therefore the findings may not be transferable to other types of incurable cancer or other incurable diseases. Importantly, metastatic prostate cancer has a longer survival time than other metastatic cancers and therefore potentially a longer time frame to adjust expectations and reflect on the value and definition of the end of life. Prostate cancer treatments on the CDF were also predominantly oral (three patients were taking intravenous CDF prostate cancer treatments) and this may have had an impact on quality of life different from other cancer types. It was difficult to recruit patients with colorectal cancer, in part because of their greater morbidity during anti-cancer therapy for metastatic disease, as described by their clinicians, and apparently stronger gatekeeping amongst the health professionals. Gatekeeping in palliative care research is common with the most common health professional barrier being a 'fear of burdening vulnerable patients' [27]. All patient participants were on CDF treatments and therefore we cannot generalise themes from these participants to those patients who were eligible for, but elected not to take CDF drugs and therefore may profess different feelings about the CDF and the value of the end of life. Clinicians advising the study group felt they had no patients who fell into the latter category of patients declining CDF treatment. It is also plausible that consciously or unconsciously, oncologists selected patients for invitation to the study based on particular views on cancer care which could limit the generalisability of our findings. However, participants shared a diverse range of views and emergent themes.

There is growing recognition of the need to understand and be able to measure the value of life at the end of life to inform policy decision making [28]. This work contributes to that literature. This research is unique in gathering patient and professional experiences of using the CDF. The work was conducted rigorously with dual coding of a sample of transcripts and analysis using constant comparison techniques. Recruitment took place across different settings (a teaching and district hospital for patients and three district and one teaching hospitals for health professionals).

4.3. Implications for research and practice

2016 saw significant change in cancer policy. The small patient population criterion (of no more than 7000 eligible patients) to be eligible for the NICE End of Life criteria was removed [29], and the CDF was reabsorbed into NICE as a managed access fund. As a managed access fund, a conditional recommendation can be provided by NICE so that a drug may be accessed through the CDF for a predetermined period of up to two years while further evidence is gathered for appraisal towards routine commissioning or rejection [30]. It is important to reflect on the apparent values which underpinned the CDF and the EoL criterion- e.g. a pre-eminence of cancer at the end of life and consider how these values continue to influence prioritisation decision making today. The prioritisation of cancer above other health states is not justified based on the vast majority of participant perspectives from this study, despite participants being able to rationalise the reasons why cancer has traditionally been a greater focus for health spending. Ongoing prioritisation of anti-cancer drugs, over other drugs, through the facilitation of their entry to the market without equivalent trial evidence as for other drugs is also called into question by these expressed value judgements. The Health Select Committee stated "We believe that the decision by NICE to raise its cost per QALY threshold for end of life drugs is both inequitable and an inefficient use of resources" [31]. And the majority of NICE Citizen's Council members were against "special consideration for treatments that are life-extending" (65% or 19/29 members against) [32]. Justification for the existence of the Cancer Drugs Fund, where cancer was prioritised over other disease states, was not found in patient and professional interviews. Although the majority of values elicited from patient and professional participants in these qualitative interviews do not represent values that justify the EoL criterion, a minority of participants agreed with the prioritisation of the EoL, and therefore, in principle, the EoL criterion. More research needs to be done focusing on this issue- eliciting more information about quality of life perceptions at EoL and enabling people to understand the costs.

5. Conclusion

The conflicting desire to 'do everything' for the individual, while being 'fair' to the population was a sentiment expressed by professional and patient participants -the majority of whom felt uncomfortable that cancer was being given special consideration in the CDF. Although there was limited support for the current implementation of the NICE EoL criterion, conflicting views between those who perceived that the time at the end of life may have more value- and those that did not - raise significant challenges for policy makers. Better understanding of the experiences of patients with incurable cancer and their professionals, in relation to quality of life at the end of life over simply time at the end of life, may be needed to help inform future policy making.

CRediT authorship contribution statement

Charlotte Chamberlain: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing - original draft, Writing - review & editing. **Amanda Owen-Smith:** Supervision, Formal analysis, Funding acquisition, Validation, Writing - review & editing. **Fiona MacKichan:** Supervision, Writing - review & editing. **Jenny L. Donovan:** Conceptualization, Methodology, Supervision, Funding acquisition, Validation, Writing - review & editing. **William Hollingworth:** Conceptualization, Methodology, Supervision, Funding acquisition, Writing - review & editing.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.healthpol.2019.05.022.

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