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Patient and family caregiver perspectives of Advance Care Planning: qualitative findings from the ACTION cluster randomised controlled trial of an adapted respecting choices intervention

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ABSTRACT

Advance Care Planning (ACP) is widely regarded as a component of good end-of-life care. However, findings from a qualitative international study of patient and family caregiver attitudes and preferences regarding ACP highlight participants' ambivalence towards confronting the future and the factors underlying their motivation to accept or defer anticipatory planning. They show how ACP impacts on, and can be determined by, relationships between patients and their family caregivers. Although some patients may welcome the chance to engage in ACP a tendency towards either therapeutic optimism or fatalism can limit its perceived appeal or benefit. The focus on individual autonomy as an ethical principle underlying ACP does not resonate with real world settings. Many patients naturally orient to share responsibility and decision making within the network of significant others in which they are embedded, rather than exert unfettered freedom of 'choice'.

KEYWORDS

Advance Care Planning; qualitative research; cancer; end of life care; Respecting choices

Introduction

Advance Care Planning (ACP) is promoted internationally as a component of good end-of-life care, particularly in high income countries (Liu et al., 2020). ACP provides individuals with an opportunity to consider, discuss and, if they wish, document, their goals and preferences for future care and treatment (Rietjens et al., 2017). It provides a mechanism for precedent autonomy should the individual become unable to make independent decisions about future care (Fleuren et al., 2020). However, a considerable research effort

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has failed to establish firm evidence regarding the impact and effectiveness of ACP (Jiminez et al., 2018; Johnson et al., 2018; Korfage et al., 2020; MacKenzie et al., 2018; Weathers et al., 2016).

Research findings generally report professionally constructed criteria of ACP effectiveness which are amenable to measurement (Biondo et al., 2016). These are taken as proxy indicators of patient centred and high-quality end of life care. They include an increase in the number and availability of documented ACPs, the proportion of deaths occurring in the patient's preferred place, completed Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms, and reduced hospitalisation and associated health care costs (Biondo et al., 2016; Jiminez et al., 2018). Patient experience and public appraisal of ACP have not been widely investigated (McIlfatrick et al., 2021; Musa et al., 2015; Sudore et al., 2018; Zwakman et al., 2018a).

Internationally, the legislation underpinning ACP, and its practice, varies widely (Rodado et al., 2021). However, even within countries such as the UK and the Netherlands in which ACP is well established and considered to be a component of good end-of-life care its practice is not widespread (Boyd & Murray, 2014; Knight et al., 2020; Matthijs et al., 2010). Barriers to implementation include reluctance on the part of professionals and patients to raise the subject and uncertainty about which professionals should assume responsibility for undertaking the discussion, and when this should be initiated. ACP tends to be carried out in a reactive and ad hoc, rather than a planned and pre-emptive basis (Bernard et al., 2020; Boyd et al., 2010; Pollock & Wilson, 2015; Simon et al., 2015). Qualitative research has reported patient ambivalence about confronting the future and a preference to remain focused on living in the present alongside the persistence of therapeutic optimism (Arantzamendi et al., 2020; Barnes et al., 2011; MacArtney et al., 2017; Peck et al., 2018; Richards et al., 2013) and a reluctance to burden friends and family members (Elliott & Olver, 2007; MacArtney et al., 2016; Pollock & Wilson, 2015; Thomas et al., 2004; Young et al., 2003). In particular, there is evidence that many patients do not approach ACP as autonomous agents making personal choices about future care, but naturally situate such decisions within the context of the relationships they have with others and the consequences their illness and care will have for these (MacArtney et al., 2016; Pollock & Wilson, 2015; Robinson, 2011; Young et al., 2003). Uncertainty remains about how ACP should be constituted in different contexts, its role and value for different groups of patients, and the criteria by which its efficacy can be confidently and reliably evaluated (Johnson et al., 2018; Morrison, 2020).

In this article we present findings from a qualitative study of patient and family caregiver experience and perspectives of Advance Care Planning (ACP). This was an embedded sub-study of the ACTION trial, a phase III multicentre cluster randomised controlled trial that evaluated the ACTION Respecting Choices (RC) ACP intervention (hereafter 'the intervention') in patients with advanced cancer (Trial Number: ISRCTN63110516). The trial recruited patients with advanced lung or colorectal cancer in six European countries (Korfage et al., 2020). The qualitative sub-study aimed to explore the patient and family caregiver experience of, and responses to, the intervention in four of these countries (UK, Italy, Netherlands and Slovenia). The sub-study findings became especially salient when the trial results revealed no significant effects on patient quality of life, symptoms, coping, patient satisfaction or shared decision making (Korfage et al., 2020).

Respecting choices

Respecting Choices (RC) is an internationally established structured ACP programme (MacKenzie et al., 2018). The adapted version used in the ACTION trial involved one or two structured conversations (according to preference) between the patient, her nominated personal representative (PR), usually a relative, and a trained facilitator (Zwakman et al., 2019). Their purpose was for participants to explore and share their goals, hopes and preferences regarding future treatments, outcome and end-of-life care. The audio recorded interventions ranged between 29 and 128 minutes in length. Patients were offered the opportunity to document their preferences, and nominate a personal representative, on a 'My Preferences' form, developed for the ACTION trial, and to share this with family and health care professionals if they wished (Box 1) (Zwakman et al., 2019). The qualitative study aimed to explore patient and PR experiences of the intervention, and how they felt it had impacted their understanding and decisions about treatment options, outcomes and end-of-life care.

Materials and methods

The qualitative study involved longitudinal patient-centred case studies to explore participants' perspectives gained from the analysis of different data sources and over a period of time (Stake, 2006). Patients in the qualitative study constituted a separate sample from those participating in the ACTION trial. They were identified through the same inclusion criteria and recruitment strategy and received the same ACTION Respecting Choices ACP intervention (Korfage et al., 2020). Patients and their PRs were invited to take part in a semi-structured qualitative interview approximately two weeks after completing the intervention. A follow up interview was requested three months later, to explore the impact of the intervention over time. Qualitative interviews were carried out by experienced researchers from a range of academic and professional disciplines (sociology, nursing, psychology). Patient-focused case studies were developed, comprising all data relevant to each case: research interviews, recordings of the ACTION Respecting Choices ACP intervention conversations; researcher field notes and completed My Preference forms (if patients chose to share these with the research team).

Patients with stage III or IV lung cancer or stage IV or metachronous metastases colorectal cancer, with a World Health Organisation status of 0–3 and an expected life expectancy of at least three months were eligible for inclusion in the study. Potential participants were approached by staff from oncology services who offered an information pack to eligible patients interested in taking part in the study. If they agreed, patients were contacted by the researcher following completion of the intervention, and an initial interview was arranged. Written consent from all participants was obtained prior to data collection which was carried out between January 2017 and July 2018. Semi structured interviews were conducted in the patient's native language, drawing on a topic guide developed collaboratively between researchers from the four countries taking part in the qualitative study (UK: KP, GC and JS; Netherlands: MK and MZ; Italy: GM, AT, FB; Slovenia: HK, UL). With permission, interviews were tape recorded, transcribed and anonymised prior to analysis.

Analysis

The research team evolved ways of working which were similar to those described in other international qualitative studies (MacArtney et al., 2020; Seymour et al., 2015). Data analysis was based on a thematic comparative within and cross case analysis. This involved all data sources and the development of detailed narrative summaries of each case. We focused on an integrated analysis of all triangulated data sources rather than a cross-country comparison. We did not have resources to translate all interviews and ACTION Respecting Choices ACP intervention transcripts into English, which was the language of the international project. All case study data relating to the first completed English and translated Italian cases were initially coded by members of the teams from all four countries. Coding was compared, collated and used as the first iteration of a collaborative coding frame for thematic analysis of the intervention and interview data. This was developed through further comparative work on single cases from Italy, Slovenia and the Netherlands which were translated into English. MZ undertook the task of synthesising initial coding into a single framework which was then used as the basis of coding the remaining case studies which teams undertook in their own language. Each team then developed the analysis and coding frame through working on their national patient cases. Data from the UK cases were available to all members of the qualitative study teams without translation. Data content and analysis were discussed during regular Skype meetings and email correspondence between researchers from all teams as well as extended face to face discussions at an annual project consortium meeting. In addition, a detailed narrative summary of each case was written in English using a template developed from the first UK case. This included translated extracts from the interventions and interview transcripts. The summaries were an important means of enabling members of all teams to access, discuss and compare the data from the different countries.

Ethical approval

Ethical approval was obtained from the Research Ethics Committee in the coordinating centre Erasmus MC (NL50012.078.14, v02) and from the relevant local Research Ethics Committees in each participating country.

Results

Case studies were developed for each of the 20 participants in the qualitative study: four from Italy, five each from Slovenia and the Netherlands and six from UK. Despite aiming for a roughly equal distribution, only four patients had colorectal cancer. Eleven patients were male. The age range was 50–88 years. Sixteen patients were married or living with a partner; two had no children. Of the 15 patients for whom the information is available, four had completed secondary education, six had a post secondary or vocational qualification and five had a university degree. Twelve PRs were the spouse, partner or, in one case, friend of the patient; five were adult children. Three patients did not nominate a personal representative. Twelve patients took part in a single ACTION Respecting Choices ACP intervention conversation and eight completed two. Thirty- nine qualitative interviews were completed with patients

and personal representatives. Twenty-one were undertaken jointly, 13 with either the patient and five with a PR alone. Four patients died or became too ill to take part in a follow up interview. Eleven completed My Preferences forms were shared with the research team. Participant identity codes following the data extracts below indicate the country (e.g.UK), the type of participant (Patient: P or PR: Personal Representative), and the source (interview (int) or intervention (RC IV)) e.g. UKP01 int 1.

Living well in the present

A good way to gain insights into individual goals and aspirations for the future was through exploration of how people situated themselves within the present. Participants prioritised the strength and importance of their relationships with family and significant others, and the desire to spend time with those who were most significant to them. Awareness of mortality prompted a re-appraisal and strengthening of these bonds. Retaining functional independence and not imposing too much burden on others were important. Alongside some regret for lost capacity due to illness, participants tended to focus on the positive, and the satisfaction to be derived from living well through the maintenance of familiar routines and everyday pursuits. A 'good day' was typically described in the following terms:

I want to be able to move about like I am, do what I'm doing, trying to push myself forward and get on with my life, as best I can, as best I can. Get on with my life as best I can.

UKP05 interview1

Oh, I don't know. Just doing what I want to do, every day. Yeah, I don't find that I'm not living well at the moment.

UKP03 RCIV

A strong theme was a preference for taking each day as it came, living in an extended present, rather than focusing too clearly on an uncertain worrying and unwelcome future. Indeed, while aware of the terminal nature of their illness, some patients preferred not to subject the future to overly close scrutiny.

... I am seeing my condition as getting better. If it will get worse at some point, I will deal with it then. Because if I would do this now my quality of life would suffer.

SLP03 RCIV part2

Considerable effort could be required on a daily basis to manage the patient's illness and its treatment in such a way as to create and maintain a life worth living. Maintaining a positive outlook was an important aspect of this strategy which could be undermined by too close or frequent scrutiny of what the future held in store.

Therapeutic optimism

Alongside a preference for living in the present was a strong orientation to therapeutic optimism. Participants often moved between acknowledgement of their limited prognosis and hope that their present, relatively good, state of health could be maintained.

They anticipated that their treatment would be effective in containing the cancer for an indeterminate, perhaps even an indefinite period. Several admitted to maintaining hope that they would, after all, be 'cured'.

I hope I will recover though it's always more complicated to move myself closer to what I was 10 days ago. But let's say the spirit is still there ... even though I always hope to get better, then I realise it is difficult to get better and would be nice to stay as you are

ITP01 interview2.

The desire to avoid anticipating or confronting future deterioration conflicts with the motivation to undertake ACP. This required a very focused consideration of unwelcome future outcomes, and how these should be addressed. Participants often expressed ambivalence, shifting between consideration of the future and a desire to close this off. They were also selective about which ACP topics they were prepared to consider at this time.

Orientation to future planning

Several participants expressed a fatalistic attitude. This perspective provided an alternative form of resistance to ACP.

I don't foresee, I don't think for the future. I don't think about, and I don't want to ... I'm not interested in that. What's going to happen is going to happen ...

UKP03 interview2

In this case, planning was felt to be pointless, because the future was intrinsically uncertain and not amenable to personal modification or control.

Alongside the desire to avoid confronting the future, participants expressed the view that they were currently too well to need to contemplate the future or make plans for unwelcome developments which may not arise and were distressing to contemplate.

Facilitator: You don't want to think about possible scenarios.

SLP06: I will think about it if it happens.

Facilitator: But you don't want to think ahead about it.

SLP06: It would only be burdensome. Now it's important that I get cured as much as possible.

SLPR06: ... We're hoping for a cure now. We'll arrange this later, if things will get worse.

RCIV

Participants were often fooled – or perhaps were willing to be fooled – by their apparent wellness, even when tests results indicated that the illness was progressing. Continuing to receive active treatment for their disease encouraged a positive outlook. Feeling and looking well, as some patients reported, were taken as evidence of *being* well.

H[consultant] was quite clear that this type of cancer, the prognosis is quite poor. But, I've just been positive, I mean, it's now, over eight months, and I feel better. So, I think possibly, could be more than two years, the way I feel, at the moment. Yeah.

UKP01 RCIV

The severity of illness and its consequences also tended to be normalised. Some patients clearly did not realise, or at least acknowledge, how gravely ill they were. Consequently, they felt that decisions about future care could be postponed until later, after deterioration had occurred and it became clear what options were available. Optimism could be combined with fatalism or even pessimism, as participants switched registers at different points in the conversation. However, a commitment to either optimism or fatalism can work against receptiveness to ACP because it is not perceived to be directly or presently relevant.

Resuscitation

Twelve patients had opted against resuscitation.

No resuscitation. Not even with a defibrillator. She told me that resuscitation might lead to some injuries. I said I don't want it.

SLP01 interview1

However, a substantial minority of patients (eight) opted *for* resuscitation. They felt their current condition was good enough to warrant continuation of life, and to take every chance to prolong this. If this should change in future, so would their decision.

At the moment, because I feel so well, ... I would want to be resuscitated if anything happens. But obviously, if it comes to the stage that I've got no capacity to give consent or, then, the medical staff ... will make that decision. Then, obviously, they will decide ...

UKP01 interview1

As the preceding extract indicates, some patients expected, perhaps even desired, that momentous medical decisions about their lives, including whether they should be resuscitated, should be undertaken by professionals. They also had difficulty situating ACP as a plan which could potentially be enacted in the near, rather than the distant, future. Thus, participants were able to specify conditions that might arise which would make life not worth living. Typically, this included states such as experiencing unbearable pain, 'becoming a vegetable' or 'being hooked up to machines. However, they opted for resuscitation, or other forms of active treatment *until* such situations arose or looked imminent. As indicated above, the tendency to therapeutic optimism could undermine a sense of urgency about the present relevance of anticipatory planning.

Preferred place of death

Ten participants stated a preference to die at home, if possible. One other opted for home or hospice. Five opted for hospice and one for hospital. Three patients had no recorded preference. As with DNACPR decisions, several had discussed and documented

their preferences prior to taking part in the ACTION study. However, the strength of preference for this outcome varied. Commonly, stated preferences for place of death were provisional, contingent on the unfolding circumstances of the illness and the capacity of family to cope with care at home. The desire to avoid 'being a burden' was strongly expressed.

Yes, we have discussed that . . . we discussed that beforehand too, but we haven't really decided yet, what we are going to do. Will I go to a hospice, will I stay home, or will I go to the hospital? We haven't decided yet

NLP01 interview1

And she asked, it was one of your people that asked me where I wanted to finish, you know, my life. And I says, 'Well, I'd like to do it at home'. I says. 'But the trouble is, it's going to be so much pressure on everybody, I'll go hospital or hospice'

UKP05 interview1

In this, as with many aspects of ACP, the fact that end of life decisions may be stated or documented does not mean that they represent stable and committed decisions or that patients were confident and happy with these outcomes.

Selective treatment vs comfort care

The ACTION Respecting Choices ACP intervention asked patients to consider their preferences regarding a ceiling of care and continuation of active treatment following deterioration in their condition. This often proved to be the most difficult question for patients to understand and for facilitators to explain. In some cases, it remained unresolved. Six patients opted for active care, six for comfort care, three were uncertain, and five gave a complex response. At present they would opt for active treatment, but accepted this position might change in future, if their health substantially deteriorated. The difficulty of answering the question about preferences for future care prevented several patients from completing the My Preferences form.

I mean, I looked at the forms of, after you came, sort of, a couple of weeks or so later, I started filling it in. And then, just a bit about the medical bit, what would you expect, sort of in terms of the, your treatment and care, I left it blank. Because, I thought, I feel well, I can't think of what I expect, I mean, sort of, in myself, I thought, if I get very poorly, all I expect is just to be looked after, sort of, as somebody would in hospital. And that's it, really. . . . So, I don't think about all these things, I just don't, don't think about it. No.

UKP01 interview2

Most participants were receiving treatment of some kind at the time of the study, active or palliative. They were accustomed to calibrating their progress through treatment effects and test results. The prospect of effectively giving up hope of treatment efficacy could be very frightening. Even those who were adamant that they did not wish to be kept alive by machines or 'to become a vegetable' sometimes recoiled from the choice of comfort care only. Active care was considered appropriate and desirable in the present. Decisions

about future care could be left until later if the need arose. In several cases, it was suggested that such decisions were more appropriately to be made by professionals, rather than patients.

Whatever the doctor wants, antibiotics or whatever. But, if I'm already weak and semi, even semi-dependent, just, for goodness' sake, if I get pneumonia, just let me go. For goodness' sake, don't pile on the antibiotics

UKP06 RCIV

Patients found it hard to envisage how they would feel in future situations and anticipated their preferences would change in future.

Just to talk about it is unpleasant, because it is quite different to talk about this issue when you feel good and when you feel ill. One year and half ago I was much more resolute about what I would want and what I wouldn't want; instead, right now when you are in an illness situation the doubts are a lot.

ITP02 RCIV

A few patients expressed a desire for hastened death when things got tough, particularly if pain became unbearable or they became dependent on others for basic personal care.

Completing the my preferences (MP) form

Eleven My Preferences forms were completed and shared with the research team. However, few participants reported discussing these, or their participation in the ACTION study, with health care professionals who were not also involved in the research. Four UK and three Netherlands participants reported that they had previously made, and documented, some decisions, such as preferred place of death and resuscitation. Consequently, the novelty and impact of the intervention form may have been lessened. A few participants described feeling glad that they had completed the My Preferences form and felt that it was important that they had done so.

It was a liberation that they know what I want.

ITP03 interview1

Others described the ambivalence they felt about this task, and their reluctance to make commitments to the future, or formalise these on paper.

I could not decide on the questionnaire. This let me know that, even though I can talk about it, I am not completely ready yet

SLP04 interview1

The shifting, equivocal nature of patients' standpoints to this issue is illustrated in the following extracts from different points in the same interview.

It reassures me that my preferences are written there.

ITP02 interview1

The My Preference form is on my bookcase at home. It was emotional to fill in it, because it is like putting down in black and white something that I would like to push out. How can I say [...] the document, the paper makes it real.

ITP02 interview1

The role of the personal representative

Seventeen patients nominated a PR. In most cases it was obvious to both parties who this should be, and the PR accepted the role willingly. Some welcomed a clear directive regarding the patient's preferences, regardless of whether they personally agreed with them, as a means of eliminating doubt and reducing personal responsibility for difficult decisions that might arise in future. Some PRs (especially in UK and Netherlands) had already discussed issues relating to the patient's end-of-life care and future preferences. However, the intervention provided a valuable opportunity to open up a discussion of these issues, regardless of whether they were being explored for the first or a subsequent time. This could be very challenging. Participants commented on the discussions bringing home the reality, and sometimes imminence, of the patient's mortality. Where there was a strong cultural or family preference in favour of preserving life at all costs, it could be instrumental for relatives to be made aware that this was not necessarily the patient's priority, enabling them to come to terms with the reality and consequences of opting for comfort rather than active and aggressive future care.

Also, for me, because I also have to let go. I can say that I won't let him go earlier, maybe we can gain some time together. But how? We've always said, also before he got ill, that we won't do this to each other, when you love each other than you have got to let go. So that it will be good for the other person. NLP04PR Interview2

In addition to their PR, many patients operated within a wider social network of close family members, especially adult children, and friends. They naturally expected members of the wider network to be involved in discussions and decision making about their future care.

Impact of the ACTION RC ACP intervention

Participants varied widely in their assessment of the intervention. Some felt this had been of great value, others were indifferent. Most were reasonably positive about the experience, especially regarding the facilitators and how these had guided the conversation.

The ACP has helped me, or will help me in the future, to better understand what the disease is.

ITP01 interview1

These conversations were helpful because they made easier to talk with my children.

ITP03 interview1

Participants valued the chance to review and reflect on established decisions, but rarely reported that the intervention had resulted in a change or reformulation of existing preferences. Quite often participants were vague and forgetful about the intervention and what had been discussed.

Researcher: Was there anything new for you? Maybe something you did not think of before.

SLP04: I don't know. I don't remember. Do you remember (to PR)?

SLPR04: It is hard for me to comment. For me there was nothing new. Maybe the things we discussed, when discussing resuscitation for example. Is it terminal? The other option was that it is not related to your illness. I think we have never before discussed these issues.

(Interview –1)

In some cases, it seemed to be the personal representatives rather than the patients who had benefited most directly from this experience, even when they found it distressing to be confronted with the patient's mortality.

UKPR01: I think it's been, it's had a positive influence ...

UKP01: Yeah.

UKPR01: ... I would say. More, because, there's certain things that I didn't think of, or, we didn't have the conversation, me and you ... I've become certainly more realistic about things ... because we didn't talk about that stage of your life that may come, may not, God knows, so I think it's had a positive influence. It's made us more able to talk, we've talked about it, haven't we?

UKP01: Mm, yeah.

UKPR01: So, yes. I'm pleased we did have that conversation.

(interview 1)

The intervention discussion also offered an opportunity for patients to acquire additional information about their illness and future treatments.

Discussion

The findings presented in this article contribute to an understanding of the barriers and disincentives to undertaking ACP in real world settings (Bernard et al., 2020; Peck et al., 2018; Pollock & Wilson, 2015) as well as the benefits that patients and family caregivers can derive from the experience (Zwakman et al., 2018a). They provide context for the outcomes of the ACTION RCT (Korfage et al., 2020) and many other studies which have failed to date to establish strong or consistent evidence regarding the 'effectiveness' of ACP (Biondo et al., 2016; Jiminez et al., 2018; Johnson et al., 2018, 2018; MacKenzie et al., 2018; Morrison, 2020; Weathers et al., 2016).

International differences

While support for the principle of individual autonomy is strong throughout all European countries involved in the study, there are clear differences in the extent to which ACP has an established place in health policy and clinical practice (Jiminez et al., 2018; Rodado et al., 2021). In the Netherlands, euthanasia is a legally sanctioned option, and the focus of most discussion of future planning. However, even in countries such as the UK and Netherlands in which ACP is supported in law, take up among the population remains uneven and low (Knight et al., 2020; Matthijs et al., 2010). In Slovenia and Italy, anticipatory planning is considerably less well established (Di Paulo et al., 2019). Although the number of participants was too small to be more than suggestive, these differences were reflected in the ACTION study data. Most patients from the UK and the Netherlands had discussed and sometimes documented aspects of ACP prior to taking part in the study. Two patients from the Netherlands had completed euthanasia plans. In contrast, ACP was a more unfamiliar prospect for patients from Italy and Slovenia. The data suggest that participants from these countries were more likely to find the ACP intervention novel, challenging, but also valuable.

Diversity, conflict and uncertainty in patient perspectives

Patients and family caregiver responses to the ACTION Respecting Choices ACP intervention were varied and complex. Participants' accounts align with many of the themes reported in the qualitative literature (Johnson et al., 2016; Zwakman et al., 2018b). They combined a range of perspectives, sometimes conflicting, within and between interviews and ACP discussions. Optimism could follow fatalism and confidence could be replaced with uncertainty (MacArtney et al., 2017). For some patients, maintaining ambiguity and uncertainty could be a preferred and constructive coping device (Arantzamendi et al., 2020; Nierop-van Baalen et al., 2019; Richards et al., 2013). Some participants acknowledged knowing that their illness was terminal and that treatment could only contain its progression. Nevertheless, they still maintained hope for a cure (Arantzamendi et al., 2020; Barnes et al., 2011; MacArtney et al., 2017; Nierop-van Baalen et al., 2019; Piers et al., 2013; Richards et al., 2013; Robinson, 2012). These findings resonate with Totman et al. (2015) depiction of different ways of 'knowing' about the reality and inevitability of dying from a rational as opposed to emotional perspective.

Living in the present with hope for the future

ACP encourages patients to anticipate and plan, particularly about their preferences for future care. However, a strong theme was patients' desire to orient themselves in the present, and to focus on living well through maintaining normal everyday activities and routines and prioritising relationships with significant others around them (Arantzamendi et al., 2020; MacArtney et al., 2017; Piers et al., 2013; Pollock & Wilson, 2015; Zwakman et al., 2018a). The effort to cope with the here and now, to manage the considerable demands made by the illness and its treatment and to maintain for as long as possible a life worth living, displaced a focus on a future orientation. Even when they acknowledged the gravity of their illness and limited prognosis, patients tended towards therapeutic optimism and the anticipation of an extended, but indeterminate, future. Feeling (reasonably) well, as many patients did, was taken as evidence of *being* (relatively) well and certainly far from death. The hope for recovery coexisted with the acknowledgement that it could not happen, and people shifted position between different interpretive repertoires according to context (MacArtney et al., 2017; Nierop-van Baalen et al., 2019; Piers et al., 2013; Pollock & Wilson, 2015; Richards et al., 2013).

Distancing from an uncertain and unimaginable future

ACP refers to a time when the individual's health has deteriorated to a point where difficult decisions must be confronted: a challenging and unwelcome prospect. Some study participants knew they looked towards a short horizon and welcomed the opportunity the Respecting Choices ACP intervention provided to enable their PR to fully understand and acknowledge how seriously ill they were. More often, participants felt able to distance themselves from the prospect of imminent deterioration and mortality. Stated preferences were commonly indicated to be provisional, contingent on future developments and the capacity of family members to cope, especially with care at home. Patients' desire to maintain their independence and to avoid imposing a burden of care on family members was often a key consideration in shaping and anticipating options for future treatment goals and settings (Bausewein et al., 2013; Elliott & Olver, 2007; MacArtney et al., 2016; O'Sullivan & Higginson, 2016; Thomas et al., 2004).

Participants found it difficult to predict how they would feel about circumstances which they could not easily anticipate, or even imagine, and which might not even arise. Many people lack knowledge or experience to be able to imagine clearly, for example, the choice of active or comfort care and the consequences of ventilation, artificial nutrition or hydration. Most patients lacked detailed and technical information about illness trajectories, treatment options and outcomes required to make realistic assessments of goals of care (Morrison, 2020; Young et al., 2003). As Drought and Koenig (2002) observe there is an 'incommensurability' between lay and medical values and knowledge. There is a risk in this case that people will choose precipitously and perhaps unwisely (Sudore et al., 2010; Young et al., 2003). Neergaard et al. (2018) observe that most ACP research does not differentiate between whether patients are stating ideal rather than pragmatic preferences, for example, between place of care and place of death. ACP encourages patients to plan future care in a situation of uncertainty. However, qualitative data, including findings from the ACTION study, highlight the extent to

which patients are hesitant in committing to decisions regarding an intrinsically uncertain future and pragmatic in formulating these as options contingent on the circumstances that unfold rather than as overriding priorities for care. This may be one reason for reluctance to formally document preferences and for some patients to opt to trust the judgement of others and to delegate responsibility for decisions about future care (Ekdahl et al., 2010; Johnson et al., 2017). Ambivalence about specific decisions, and the *constraints* imposed by these may be one reason for reluctance to document preferences (Johnson et al., 2017; Musa et al., 2015; Pollock & Wilson, 2015). Committing to a specific action forecloses other options and thus presents patients with an ideological dilemma (Billig et al., 1988). ACP may be experienced as narrowing and limiting, rather than expanding, choice (Johnson et al., 2018).

Timing and 'being ready' to talk

The importance of 'readiness' and timing of ACP underlies the reality that although it may benefit some patients, it may be irrelevant, or even harmful, to others (Hopkins et al., 2020; Johnson et al., 2016; Peck et al., 2018; Simon et al., 2015; Zwakman et al., 2020). Professional concerns about causing distress or damaging relationships with patients are frequently cited as barriers to undertaking ACP (Pollock & Wilson, 2015; Zwakman et al., 2019). Consistent with cultural norms about the desirability of maintaining a positive attitude of mind, the preference for limited awareness and a selective ambiguity about prognosis can be a powerful device for coping and maintaining hope (MacArtney et al., 2017; Nierop-van Baalen et al., 2019). While a sense of certainty and control may be helpful for some, the immense significance of anticipatory decisions, alongside intrinsic uncertainty about prognosis, may produce anxiety and decisional conflict in others (Piers et al., 2013). Piers et al. (2013) highlight the risk of ACP encouraging 'pseudo-participation' in decisions about future care that the individual lacks sufficient knowledge to assess and understand and which refer to future scenarios which are beyond the power of her imagination to realistically envisage (Young et al., 2003). In such circumstances patients may look to professionals to guide decisions about future care in preference to assuming personal responsibility for these (Barnes et al., 2011; Ekdahl et al., 2010).

Strengthening relationships through shared understandings

Some PRs were happy to know, or to confirm, patient preferences. Patients' desire to reduce their relatives' burden and responsibility for future care and treatment decisions was a strongly motivating factor in undertaking ACP. However, caregiver responses to assuming the role of proxy are reported to be variable and to increase as well as reduce decisional distress and burden (Robins-Browne et al., 2014; van Eechoud et al., 2014; Zwakman et al., 2019). Decisions about future care were often considered to be a relational process involving wider family and friends, rather than an expression of personal autonomy and choice (Elliott & Olver, 2007; Johnson et al., 2016; Musa et al., 2015; Robins-Browne et al., 2014; Robinson, 2011). It was the strengthening of current inter-personal relationships which followed from shared understandings and open communication, rather than specific decisions about future care, that could be the most valued aspect of the intervention (Robinson, 2011; Zwakman et al., 2019).

Relational autonomy

The study findings are framed within a critique of the prioritisation of a neoliberal view of patient autonomy and choice as a rationale for ACP (Sherwin, 1998). Whilst undoubtedly important for some, it does not resonate with the experience or priorities of many patients and risks imposing anxiety and decisional conflict on those who cannot imagine, or prefer not to anticipate, the details of an unwelcome and uncertain future. The study findings support those from a growing body of qualitative literature which highlight the distance between policy assumptions and priorities and the real world responses and concerns of patients and their family members and the way they make decisions (Johnson et al., 2017, 2018; Piers et al., 2013; Robinson, 2011). Rather than valorising personal choice and autonomy most patients privilege their relations with significant others and their capacity to maintain their social roles and connectedness within these. Thus, they naturally orient towards relational rather than precedent or individual autonomy (Elliott & Olver, 2007; Johnson et al., 2016; Robinson, 2011). Decisions are made in consideration of the consequences they will have for others as well as the self. Rather than encouraging formalisation of decisions about future hypotheticals which patients may have limited knowledge or capacity to imagine, the potential value of ACP may lie in activating professional support to help patients and family caregivers accept and understand the nature of their illness and its consequences and prepare themselves to make 'in the moment' decisions as these arise in future (Hopkins et al., 2020; Pollock & Wilson, 2015; Rebecca L Sudore & Fried, 2010).

Strengths and limitations

The study included a small number of cases from each of the four participating countries. However, the study design allowed triangulation of data sources relating to each case and comparison between cases within and between each country. Access to recorded in vivo ACTION Respecting Choices ACP intervention discussions between facilitators, patients and personal representatives was a particular strength of the study as was the ability to compare the content of these discussions with reflective follow up interviews with participants. Inclusion of an international perspective was also a strength of the study although differences in language and limited resources for translation restricted access of team members to all primary data. However, data analysis developed through an iterative process and sustained collaboration between the research teams in each country including sometimes robust discussion and revision to reach a working consensus about the nature and significance of key themes identified in the data. We cannot specify how many patients declined the invitation to take part in the qualitative study, but we assess the response rate to be relatively low, as it was in the intervention arm of the trial (Korfage et al., 2020). This means that the participants who agreed to take part were self-selected in their willingness to engage with an ACP intervention. The sample composition was heavily skewed towards patients with lung (16) rather than colorectal (4) cancer. The sample of participants within each country lacked cultural and ethnic diversity. With the exception of one UK patient from an Asian background all participants were from the majority White population. This reflects the wider research on patient and family experiences of ACP but is a serious limitation.

Conclusion

The study findings highlight the complex, variable and shifting perspectives which patients and family caregivers from four European countries brought to bear on ACP. They support a developing body of qualitative research which challenges conventional assumptions of policy and professional practice. The paper reports a preference for many patients to focus on living well in the present, rather than anticipate an uncertain and problematic future and to hold to a position of therapeutic optimism and temporalisation in relation to their illness progression. ACP may be valued by some patients and family caregivers, including those who have a clear illness trajectory, for whom it is important to retain a sense of personal control even in the face of great uncertainty, or who confront imminent mortality. However, several factors contribute to a degree of resistance towards future planning. A commitment to either optimism or fatalism undermines the value of planning for an uncertain unwelcome and hypothetical future. Pushed to assume the role of autonomous decision maker, patients frequently express a preference, sometimes an expectation, that professionals and/or family members will assume responsibility for making grave decisions about their future care. These findings are in stark contrast to the dominant professional and policy scripts of the purpose and delivery of ACP interventions. The ACTION study reinforces wider findings which emphasise the value of ACP as a relational and communicative process rather than a prompt for making, and documenting, individual decisions about future care. At its best, ACP can provide an opportunity for dialogue between the patient and their significant others which helps them prepare for making decisions in the emerging moment rather than a hypothetical and uncertain future.

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