UNIVERSITY OF AMSTERDAM

UvA-DARE (Digital Academic Repository)

The inherent tensions and ambiguities of hope: Towards a post-formal analysis of experiences of advanced-cancer patients

Brown, P.; de Graaf, S.; Hillen, M.

DOI
10.1177/1363459314555241

Publication date
2015

Document Version
Author accepted manuscript

Published in
Health

Link to publication

Citation for published version (APA):
Brown, P., de Graaf, S., & Hillen, M. (2015). The inherent tensions and ambiguities of hope: Towards a post-formal analysis of experiences of advanced-cancer patients. *Health*, *19*(2), 207-225. https://doi.org/10.1177/1363459314555241

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, P.O. Box 19185, 1000 GD Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (https://dare.uva.nl)

Download date:12 Nov 2026

The inherent tensions and ambiguities of hope: Towards a post-formal analysis of experiences of advanced-cancer patients

Patrick Brown – Department of Sociology, University of Amsterdam
Sabine de Graaf – Department of Anthropology, University of Amsterdam
Marij Hillen – Department of Medical Psychology, Academic Medical Center, University of Amsterdam

This is the final accepted version of the article which is now published as:

Brown, P., de Graaf, S. and Hillen, M. (2015) The inherent tensions and ambiguities of hope: Towards a post-formal analysis of experiences of advanced-cancer patients. *Health* **19(2):207-225.** Please cite this version.

Abstract:

Sociological and anthropological analyses of hope in healthcare contexts have tended to address institutional processes, especially the power dynamics that function through such systems or political economies of hope, which in turn shape interactions through which hopes are managed. This article extends this approach through a more detailed consideration of the experience of hoping itself. Our post-formal analysis denotes the tensions that are intrinsic and defining features of lifeworlds around hope, emphasising the dissonance and fragility of hoping. Drawing upon interview and observational data involving patients with advanced-cancer diagnoses who we taking part in clinical trials, we explore three main tensions which emerged within the analysis: tensions involving time and liminality between future and present; ontological tensions involving the concrete and the possible, the 'realistic' and the positive; and tensions in taken-for-grantedness between the reflective and the mundane, the specific and the ambiguous. Rather than three separate sets of tensions, those involving time, ontology and taken-for-grantedness are very much interwoven. In denoting the influence of social processes in engendering tensions we bridge sociological and anthropological approaches with a more definition-oriented literature, developing understandings of hoping and its key characteristics in relation to other processes of coping amidst vulnerability and uncertainty.

Keywords: Cancer, clinical trials, hope, lifeworld, tensions, uncertainty, vulnerability.

Introduction: the shaping of hope within healthcare lifeworlds

The sociological and anthropological study of hope within contexts of health, illness and medicine and more specifically within the context of cancer care constitutes a growing field.

As noted by Eliott and Olver (2007), sociological and anthropological research has largely addressed institutional processes involving hope, especially the power dynamics that function through such 'systems', 'cultures' or 'political economies' of hope (van Dantzig & de Swaan 1978; Good et al. 1990; Good 2001; Lerner 2001; Brown 2005; Novas 2006) and the interactions through which hopes are shaped (Miller 2000; Broom and Tovey, 2008). A separate literature, generally more applied (medical, nursing and bioethics), focuses on the nature of hope itself in terms of its central characteristics, social meaning and vulnerabilities (Kylmä et al., 2001; Simpson 2004; Eliott and Olver 2007), with some valuable insights from anthropology (Crapanzano 2003; Zigon 2009). The current study aims to bridge these two literatures, considering the subverting of hope which results from its social shaping. In particular we identify certain tensions that result from social processes as distinguishing qualities of experiences of hoping. These tensions in hope emerged as an important theme within our qualitative study, involving analysis of interviews and observations involving advanced-cancer patients.

Considering American oncology settings, Good's anthropological research into 'cultures of hope' (Good et al. 1990) or what she later refers to as the 'medical imaginary' (Good 2001) echoes more classic concerns with the extent to which broader societal 'fantasies' (Sontag 1978:19) bear profoundly upon patients' lived experiences and perceived possibilities of cancer treatment. Good (2001) shows how the *cultural*, in terms of imagination around novel technologies, the *social*, in terms of relational commitments and obligations, and *identity*-related aspects of patients' individual 'clinical narratives' help sustain one another: whereby 'affective

and imaginative dimensions of biotechnology envelope patients within a "biotechnical embrace"' (Good, 2001:397). In more sociological terms, this three-tiered conceptualisation of the shaping of patients' 'horizon of possibilities' – an everyday 'reality which seems self-evident' (Schutz 1973:3) – constitutes their lifeworld (Habermas 1987:138).

This lifeworld concept can be useful to analyses of hoping amidst cancer in various ways. First, it is a tool for organising different types of processes with which the taken-for-granted basis of personal hope narratives are interwoven: Macro-cultural processes involving institutional power and language shape patients' 'clinical narratives' and attitudes (Good 2001; Lerner 2001) within a humanist public sphere where positive possibilities are largely framed in terms of psychologised self-control (Seale 2002; Eliott and Olver, 2007) and new treatment technologies (Lerner 2001). These novel technologies, where the evidence-base is less well developed, may be seen to pose greater risks of unforeseen effects while also symbolising wider positive possibilities (Good, 2001; Brown, 2005; Broom and Tovey, 2008).

The more micro-social pertains to the ways in which these potentialities – and risks – are discussed with patients, as salient in understanding the fostering or curtailment of hopes and the related selection of one treatment path (in our case, involvement in a drugs trial) amidst other options (Good et al., 1991: 121; Gordon and Daugherty 2003; Sinding et al., 2010). The generation and maintenance of patients' hopes by the physician within some cancer contexts has been criticised as a 'collusion of misunderstanding' (Miller 2000:34; van Dantzig and de Swaan 1978). These interactions are however embedded within broader cultural and institutional contexts. For example, less biomedicalised contexts have been found to foster alternative moral dynamics of patient-professional interactions, which 'were valued, primarily, for their subjectified (rather than abstracted) and individualised (rather than depersonalised) approach to cancer care; an approach which was seen to allow for, and promote, agency, self-determinism and ultimately hope' (Broom and Tovey, 2008:43).

The second conceptual utility of the lifeworld is especially pertinent to hoping amidst advanced-cancer and relates to the impact of cancer diagnosis and prognosis on this 'horizon of possibilities'. For while the lifeworld, as a basis of hopes, is constructed by the institutional and interactional mechanisms of oncology contexts (Good 2001), a patient's lifeworld is also profoundly destabilized, fragmented or even 'shattered' (Alaszewski et al. 2006:2) by the calling into question of that which was previously taken-for-granted (Habermas 1987:400; Giddens, 1991:114). Patient's interactions with oncology professionals may involve considerations of 'statistical "likely-to-happens"' (Sinding et al. 2010:1091), with 'probable' and possible eventualities being discussed. This illumination of various potential futures amidst diagnoses of advanced-cancer and related prognoses may generate 'existential crises' (Broom and Tovey, 2008:108). Social processes around hope amidst cancer therefore do not merely shape the lifeworlds of hopers (Good 2001); they render them disjointed.

Sociological and anthropological literature exploring institutional processes around hope is rich in considerations of the shaping of hope-oriented lifeworlds but stops short of considering the ramifications of their undermining for experiences of hoping. Meanwhile, the more applied studies which focus on the concept of hope itself tend to consider neither detailed accounts of 'how hope operates in situ' (Eliott and Olver 2007:139) nor hope in specific outcomes (Wiles et al. 2008:) and are beset with difficulties in defining hope (Simpson 2004). In describing and understanding the nature of various tensions – involving time, ontology and the taken-for-granted – the analysis presented below identifies how these are in certain ways defining of lived-experiences of hoping, as well as exploring how these tensions were shaped by the social.

Towards a post-formal approach

Conceptualised as an 'emotional attitude' (Simpson 2004), that of a lens which orients the hoper towards particular phenomena (in the future), hope plays an important role in focusing attention away from vulnerability in the present (van Dantzig & de Swaan, 1978). Affective experiences of vulnerability, such as those involving despair or anxiety, exist in part because of the existence of a particular objective entity but also due to the positioning of our subjective gaze upon this entity (Kierkegaard, 1957: 55). By shifting one's gaze to the future, experiences of vulnerability are partially transcended, with desires to realise this future facilitating action rather than passivity. 'Hope as expectation' ('anticipating' that which is 'likely') has been distinguished from 'hope as desire' in more 'remote' possibilities (Wiles et al. 2008:565), though it is perhaps more useful to follow Simpson's emphasis upon the multi-dimensionality of hope within healthcare contexts – including how processes of desire, belief, imagination and action are interwoven (Simpson, 2004: 431-2; Eliott and Olver, 2007).

Exploring hope as a lived-experience of going forward amidst vulnerability, Zigon (2009) also emphasises the action component of hope. Considering the phenomenon of hope as a means of 'perseverance', he hesitates to limit considerations of hope as necessarily envisaging something more utopian or ideal (c.f. Bloch, 1986). Zigon (2009) suggests that hope involves a more 'background', or 'generalised' (Wiles et al. 2008), attitude to the present and future which aids the hoper through the everyday routines of life. Hope, however, can also involve 'a temporal orientation of intentional and reflective ethical action', assisting in overcoming existential crisis during unusual hardship and breakdown (Zigon 2009:267). The transcending of past experiences and the mundane concreteness of the present, via the possibility of the future (Brown, 2005), suggests the power of hope. Yet narratives of hope may also be fragile where there is a lack of coherence between past, present and future (Ricoeur 1990). Hope is a means of continuing amidst vulnerability (Zinn, 2008) but at the same time entails *becoming* vulnerable; vulnerable to being disappointed and therefore to information which may lead to

disappointment, not to mention the possibility of being seen by others as naive (Simpson, 2004).

In order to render its distinctive qualities further apparent, it is useful to consider practices of hope alongside related processes (Brown and de Graaf 2013). Hope is just one of several 'strategies' by which vulnerability amidst uncertainty is 'managed' in everyday life. Zinn (2008) develops a typology of these different strategies, presenting a spectrum running from the rational-calculative attributes of risk management, through strategies such as trust which harness both rational and non-rational components, towards 'non-rational' strategies such as hope. The underlying argument is that risk, trust and hope each involve different ways of working with knowledge and uncertainty (Zinn 2008). We might therefore typify the risk management approach as characterised by a particular form of rationality, through which 'explicit knowledge' (Lam, 2000) is applied in an aggregated and calculative manner (Zinn, 2008). In contrast trust can be described as invoking a more embodied and tacit manner of working with uncertainty when vulnerable (Barbalet 2009; Brown et al. 2011). Unlike risk and trust, hope is (shaped amidst but) not dependent upon knowledge from the past, hence Zinn's (2008) 'non-rational' label. Below we explore the distinctive manner by which hoping works between knowledge and uncertainty.

As Lomranz and Benyamini (2009) argue[1], the neat coherence of classic 'formal' theories must be left behind in order to do justice to the complex nature of the empirical. (See Wilkinson, 2004 for a similar argument regarding sociological accounts of suffering.) *Aintegration* – involving 'the ability to bear inconsistencies, relativism, discontinuity, paradox, ambivalence, ambiguity and contradictions' (Lomranz and Benyamini, 2009:1) – is one such 'post-formal' concept. In considering the lived-experiences of holocaust survivors, Lomranz and Benyamini (2009) argue that it is the role of aintegration (usually labelled pejoratively as 'cognitive dissonance') which was vital to describing how some 'coped' better than others. As already touched upon, and as we

will develop further below, hope too would seem to involve abiding with aintegration tensions. Rather than noting its 'non-rationality' (something of an intellectual cul-de-sac), a post-formal characterisation of hope shifts our analytical focus onto these tensions as central to the expediency, but also the awkwardness, of hoping.

Tensions are regularly implicit within the hope literature (Good 2001; Simpson 2004; Brown 2005; Eliott and Olver 2007) but have tended to be noted as asides, or explained away, rather than interrogated empirically. For example, Wiles and colleagues distinguish between 'particularised' hope (2008:565) in a rather specific outcome and a more 'generalised' hope – "...simply the possibility that things could be different from what they currently are" (Simpson, 2004:440). The suggestion though is that hopes exist along a spectrum between the two (Wiles et al. 2008), rather than awkward amalgams of both involving aspects which are more explicitly-focused upon and other dimensions which are more taken-for-granted (Schutz 1973), as revealed by our analysis of our data below.

Alongside tensions in 'taken-for-grantedness', in the data analysis below we also consider tensions in time and ontology. We referred earlier to one form of time-related tensions that exist between hope as perseverance in the present and that of a possible future (Zigon 2009). Whether hope involves probable futures or mere possibilities has also been debated in the literature (Brown, 2005), with processes of hope in some cases involving an ambivalence as to the likelihood of an outcome. The pun that is central to the meaning of utopia (in Greek, both 'good place' and 'no place') is salient in capturing such inherent ontological tensions regarding the qualities of what is hoped for in the future.

These three different tensions can be understood in light of the sociological literature described in the Introduction, regarding: undermined lifeworlds which render the taken-for-grantedness of the future problematic in terms of multiple notions of time; ambivalent ontologies of what is

expected or deemed remotely possible; and, as a result, the extent to which the future is consciously reflected upon or remains more assumed. We have identified manifold hints of such tensions within the applied literature focused on the nature of hope, though these implicit recognitions of tensions are seldom explored further. It seems plausible that some of the definitional problems within this more conceptual literature on hope (see Simpson 2004) may be due to these tensions which represent obstacles to neat 'formal' accounts. These same tensions point us towards the relevance of post-formal approaches (Lomranz and Benyamini, 2009) that also assist in considering the distinctive qualities of hope alongside other processes for coping amidst uncertainty and vulnerability (Zinn 2008). It is towards such tensions that our empirical analysis is oriented.

Data and Methods

The interview data presented in this article were collected during five months of fieldwork in the Netherlands. The initial study sought to analyse the role, relevance and interrelations of hope and trust in coping with highly elevated levels of uncertainty and vulnerability of advanced-stage cancer patients who were participating in clinical trials. In collaboration with colleagues at a major academic hospital and a smaller regional hospital, participants were purposefully recruited from a range of phase 2 and 3 randomised (controlled) clinical trials (see table 1). We sought to exclude patients who had participated in previous social research studies to avoid them becoming 'over-researched', which would have been ethically problematic. Of the twenty-five patients contacted, thirteen patients consented to participate. Motivation and reasons for not participating were not further investigated. The study was submitted to the main academic hospital's Medical Ethics Committee and given clearance to proceed.

Table 1 about here

Nine men and four women were interviewed, aged between early-40s and late-70s (see table 2 – specific ages are withheld and we have used pseudonyms to protect the privacy of respondents). The educational and work-related backgrounds of participants were rather diverse, though inclined towards the more highly educated. Two participants - Marcel and Lars - were of a minority ethnic background. The sampled patients had received various forms of cancer diagnosis (see table 1), of which pancreatic cancer was the most common (n=7), with other primary diagnoses of multiple myeloma (n=3), renal cancer (n=2) and intestinal cancer (n=1). Where possible, these interviews were followed up by an observation of the participant's regular out-patient appointment with their oncologist (n=6). These observations focussed on the format and content of patient-physician interactions which, in combination with interview data, facilitated more critical insights into the structures of patients' sense-making (lifeworlds) regarding their diagnoses and prognoses amidst interactive experiences and relationships with healthcare professionals.

Table 2 about here

In-depth interviews lasted between one and four hours and were conducted at a location of the participants' choosing (usually home, occasionally hospital). The interviews were semi-structured, with open-ended questions encouraging participants to tell their story, while probing further into patient's experiences and meaning-making of their illness, motivations and involvement in a clinical trial, as well as their ideas and perceptions of the future. Hope in most instances was spontaneously mentioned by participants during the interviews, yet inquired into more specifically towards the end of the interviews. This was to prevent the emerging interview narratives being defined by this concept as an artefact of questioning. Specific questions on hope focussed on whether patients experienced hope, the significance and meaning of hope, and where their hope was derived from.

The interviews were carried out by Sabine de Graaf, who had had recent experience of a very similar illness context involving a close family member. The personal experience of the researcher was not mentioned to the participants beforehand (see Smith et al. 2009:66), however it was acknowledged in instances when participants inquired about the interviewer's interest in the research topic. This familiarity and insight with the contexts aided in minimising the symbolic violence within intimate interview encounters (Bourdieu, 1999) facilitating open and rich interviews. However Bourdieu (1999) also warns of the dangers of familiarity, in making assumptions about the participant's experience within the interview and the intended meaning of their responses. The researcher aimed to continuously reflect upon her position within the interview, especially regarding the impact of questions (not least those on hopes and uncertain futures) on the emotional state of the participants (Gysels et al., 2008). The optional presence of a family member or spouse present (see table 2) was thus designed to offset the power dynamics between interviewer and potentially vulnerable participant. Where present, the interaction between these two 'participants' within the interview influenced the patients' narratives – giving insight into the social shaping and reworking of hope narratives as well as an understanding of the communal role of hope within the shared illness experience. The additional comments of these family members or spouses were therefore included in the data-analysis.

The analysis of the data followed a phenomenological approach, which prioritised a focus upon ongoing, embodied and negotiated processes of sense-making and expectation-construction amidst the lived experiences of uncertainty resulting from living with a cancer diagnosis (Schutz, 1972; Smith et al., 2009). Attention was therefore given to in-depth analyses and nuanced explorations of participants' accounts regarding their experiences, meanings and lifeworlds (Smith et al., 2009). Basic coding of interview transcripts began shortly after each interview, enabling newly emerging themes to be fed back into later interviews. The coding

process then developed into a thematic analysis incorporating three stages of coding: open, axial and selective (Neuman, 2000).

More specifically in relation to the analysis of lived experiences and meaning of hope presented below, 'tensions' concerning the future and hope were an initial prominent and recurring code identified in the early/open stages. This broader coding-theme was then explored in more detail and broken down into different formats of tensions in relation to the specific contexts of the participants (axial stage). The latter stage of analysis (selective) paid particular attention to understanding different data excerpts within the experiential-narratives and lifeworlds of the individual participants (Smith et al., 2009). This granted further insight into tensions as these existed within individual narratives. Double-coding and critical discussions around the coding process, also involving the researchers from the clinical setting, were carried out to increase the validity and consistency of the analysis.

Analysis

Our study illustrates well the aforementioned tensions, which were an important etic concept within the analysis, central to considerations of hope and commonly recurring across the data (apparent within 12 out of 13 interview narratives). Further refinement saw this theme nuanced further into sub-themes involving: tensions of time, ontology and taken-for-grantedness. These are discussed in turn below.

Intractable uncertainty about the future: tensions involving time

As outlined earlier, one of the defining features of hope is its relation to time: mainly through a capacity to cope with uncertainty in the future, but also via the enduring of difficulties in the present and/or transcending experiences from the past. Before we proceed to more explicit

analyses of hope, it is useful to consider the construction of participants' lifeworlds and their experiences and agency amidst these. Seemingly shaped by the limited prognoses and uncertainties that are characteristic of living with advanced-stage cancer diagnoses, assumptions and reflections upon the future and time through which patient's expected to live were important recurring topics throughout the interviews. Thomas, a man in his sixties who had been told that his cancer tumour was inoperable after having sought a second opinion, referred to the nature of his condition as rendering expectations about the future very difficult indeed.

> *Interviewer: Is it difficult to think about a long-term future?*

> *Thomas: Yes, that is difficult. That is difficult. Because I don't know, will I be here in December, or next year? Nobody can tell me. So I try not to look so far ahead. And maybe that is for the best, because you cannot oversee everything. I could not have foreseen that this would happen to me. You never know in life, anything can happen. And yeah, so in that sense you just have to seize the day. That is what is most important. And what happened in the past is of no use anymore in the end. What is done is done. And far away in the future, you don't know what is coming. So it is best to just make the most of it.*

Thomas's approach was generally one of 'bracketing away' (Brown et al., 2011) both the longer-term future and the past ('what is done is done') by an experiential dwelling in the present. The destabilising of this 'horizon of possibilities' through uncertainty also created a pliability, through the way 'anything can happen'. Accordingly the lifeworld, constructed through experiences in the past and as well as biomedical information about the future, was not defining of lived experience. Parts of the lifeworld could seemingly be 'looked past' through the wilful gaze of the cancer patient.

Other participants also struggled with the unpredictability of the future and sought to avoid it, implying a lack of hope, yet with tensions remaining as to the distance of future horizons:

> *Interviewer: Do you think about the future?*
>
> *Sanne: No, because I think you have to live by the day. It is not possible to predict what will happen. […]. My daughter plans things. In [date approximately 4,5 months in the future] there is a concert of [Dutch music band] in Amsterdam, so I have to go… So ok, well that is [date], so we just have to look forward and, ehm, then eh, then accomplish it.*

Sanne also wanted to live day-by-day and therefore, similar to Thomas, tried to 'bracket off' the future. However considerations of future-time – 'a specific quantity and quality of time envisaged in the future' (Brown and de Graaf 2013) – were forced upon her by the plans made by her daughter. This led to a tension in Sanne's account, by which the future was kept at a distance by focussing on the present, yet this active bracketing was also impeded by a planned event – through which the structure of her time 'horizon' was recast and her imagination and desire ('to accomplish') refocused. So although lifeworlds could be 'looked past' to some degree by 'bracketing' aspects away, social interactions and the plans emerging from these interactions could nevertheless generate possible futures (time structures of patients' lifeworlds). In this way social processes were influential in recasting lifeworlds and a patient's 'looking forward' within these.

The experienced 'loss' of a future, due to the uncertainty following an advanced-cancer diagnosis, was common amongst participants. This rendered 'hope as expectation' (Wiles et al., 2008) and the lifeworld that had been constructed through that 'planning' very much undermined:

Marcel: My expectations were really low, let me put it that way. I didn't really know what cancer was. We [participant and wife] made so many plans last year. We are going to do this, we are going to do that. And then everything just fell apart. […] I had no future anymore.

Whereas before his diagnosis Marcel and his wife had many plans for their future, including travelling together, seeing their daughter who lived abroad and visiting family in Marcel's homeland, after hearing he had cancer these plans became untenable.

Marcel: …Sometimes I think I do not have much longer to live, other times I think I don't want to die yet. And I, when I, when I live, I will do this and will do that. Yeah, you do make plans sometimes. But you do not make real plans anymore.

Interviewer: You mean plans in future terms?

Marcel: The short term, yes. […] You have to work with plans, otherwise you cannot cope. No, then you just sit in your chair. You have to work with plans. […] But the future I don't see anymore. I look at it this way, every month is a bonus that you live. I just try to live, you never know.

In contrast to his earlier statements regarding having 'no future' and having prepared goodbye letters written to some family members, Marcel nevertheless talked about 'making plans'. Rather than 'hopes as expectations' of the 'likely', Marcel's 'plans' seemed to relate more to 'hope as desire' in his more remotely possible plans (Wiles et al., 2008:565). This latter form of imagining futures, at least short-term futures, facilitated coping in spite of the impact of social processes that seemingly precluded a (longer-term) future.

Envisioning a long-term future was something most participants expressed as difficult, even when they did have thoughts about the future. The threat of death due to the expected

incurability of their illness remained at the back of people's minds and therefore it could be challenging to discuss the future in a positive way:

Interviewer: Do you think a lot about the future?

Ruben: Ehm, yes. In the beginning we [participant and partner] were like, where is this future going? Do we have a future together? […] But it is difficult, you know, the insecurity. If you would know what the future would hold, will this [cancer] be worse, yeah that is possible of course. Or will there be a period of time in which I feel better?

Interviewer: So do you see a positive future?

Ruben: Well, no. No, but yeah, that always sounds so gloomy, doesn't it, when you say 'no'?

Interviewer: Here it's ok [to be gloomy], so don't worry about it.

Ruben: Yes, in a short period of time, yes. The way it is going now. But yeah, the long-term future is always in the back of my mind. I have an illness that is incurable. Hopefully I hold on long enough and they will find something that can cure it; that is possible, that would be great.

One thing that most participants expressed as less uncertain was the incurability of their illness. This was understood in terms of the 'advanced-stage' of their diagnosis, with this information rendering a positive perspective towards the future rather difficult. Yet Ruben was one of several who expressed hope that his short-term survival might stretch far enough into the future that improved treatments would emerge, thus opening up new alternative futures (Brown and de Graaf 2013). As apparent in earlier data quotations, the pervasive uncertainty experienced by participants in various ways curtailed some participants' 'horizon of possibilities' but in other ways destabilised and even expanded these lifeworlds, by emphasising that many things were 'possible'. In this way Ruben's more feasible short-term survival could be stretched and then attached to more remote possibilities via hope. Hoping could accordingly rework different futures even if these were very precarious and existed amidst more generally gloomy outlooks.

The data presented in this section have illustrated how the participants' position amidst social processes of diagnosis, prognosis and treatment pulled their lifeworlds in conflicting directions, in various ways curtailing and calling into question their assumptions about futures. Yet these lifeworlds of highly limited 'expectations' could nevertheless be undermined through the uncertainty which called so much of their 'self-evident reality' (Schutz 1973) into question. Destabilised lifeworlds could then be partially 'looked-past' through 'bracketing away' the negative or by imagining various possibilities. These latter expressions of hope - timid ideas and plans - accordingly endured, despite the nature of diagnosis and biomedical understandings of treatment 'possibilities'. Tensions between making plans yet not 'real' plans, living day-by-day and seeing 'no future' yet occasionally looking forward and imagining, underline the conflicted dimensions of the future-time (Brown and de Graaf 2013) within which more or less tentative hopes could be developed.

Caught between remaining positive and 'being realistic': ontological tensions

Apparent in the data discussed above were not only tensions regarding future-time but also tensions concerning the nature of what was expected. As explained above, a subtle difference exists between hope as expectation and hope as a desire (Wiles et al 2008). The tension between these two became more apparent when participants discussed their expectations towards their participation in a trial. Lucas's participation in another earlier trial had been stopped due to drug ineffectiveness. He and his wife, who had referred to a number of negative experiences with the same clinicians who attempted to manage his hopes, described such tensions:

Interviewer: So what did you expect from the [trial] treatment?

Partner: It was explained very clearly that we should not have any expectations.

Lucas: Yeah.

Partner: But in your heart there is such a hope that it, ehm, but you cannot hope. That there ehm, that there will be a cure, that you can get better. Because that was pointed out clearly, but you do hope that it will work[2].

As this excerpt above shows, tensions arose between not being *allowed* to hope and *wanting* to hope. In part this tension seemingly existed between a patient and his partner (in their willingness to hope) on the one hand and the views of the professionals (in imposing 'realism') on the other. Yet this tension between imagined-desire and what was deemed feasible was also an internalised one, due to the weight of expert advice as it bore upon the patient's lifeworld. Lucas was observed during his next routine appointment following the interview, where he learned that his treatment had not had the desired effects and the test results appeared very problematic. Lucas seemingly sought to hide his disappointment through smiles and jokes, yet admitted after the appointment that despite his upbeat exterior that he was 'crying inside'. Tensions were not static therefore, they emerged through interactions with emotional consequences 'in your heart' but they could also be rendered unviable (stretched too far) following interactions – also with a severe emotional impact.

The tension between 'realistic' expectations and the desire and imagination involving a willingness to hope, amidst a lifeworld shaped by clinical expertise and hope management which emphasised 'realistic' or less positive outcomes, was also visible in Ruben's interview account:

Interviewer: Do you have hope for a cure, or is that taking it too far?

Ruben: Yes, I do hope for that, but it is…Hope is...yeah…no, I guess that hope is too big a word for that. I try to remain realistic, that in principle I will not be cured. I just hope, eh, it is there, you know, let me just turn 80 with what I have in me, then it is fine by me. It's been in my body

since [year] and it has remained small there for five years. […] So yeah, I think that such a period could possibly be repeated. Because that I do hope for…that my own immune system will kick in. I do hope that. Yeah, I guess that is hope. Yeah.

When quoted in the preceding section, Ruben spoke largely of short–term hopes or the possibility of a cure. However in the above quotation, despite a fragility in his hope for a cure which meant he was not even sure if 'hope' was too bold a word, he referred to a broader possibility that the length of time he has lived with a non-aggressive tumour could be extended or repeated. These different considerations about the future, some more positive than others were common within interview narratives, often incorporating tensions between having more 'realistic' hopes and the construction of plausible arguments which suggested more positive, though less likely, outcomes.

Modest, more 'realistic' hopes, which represented possibilities in the near-future – such as experiencing the forthcoming birth of a grandchild, or hoping to live a little longer – were often expressed by participants. Interestingly though, narratives of participants often eventually led back to a more 'bolder' type of hope:

Interviewer: Did you have any thoughts beforehand about the chances of success of the [trial] treatment?

Thomas: Well yes, when you start the treatment you hope it will have some effect. I have always heard, well, from the physician in training, when we start a treatment it is to bring the growth of the tumour to a stop, or to possibly reduce it, so that it shrinks. Then her supervisor, or somebody, told me that same day that I shouldn't expect that this treatment would cure me, or that the tumour would shrink. Later it was said a couple of times, well maybe it might shrink. So the doctor told me I shouldn't count on it, now they are telling me that that is an unlikely result. Because that is still my hope, that when it [the tumour] reduces, you know if it shrivels for a part, then maybe it will also move away from the artery, which would make an operation possible again.

Thomas's account contained various tensions. These tensions partly involved the conflicting, or at least changing, expert advice he received from various different professionals about what he could expect and what 'might' happen. As in the preceding section with time, we see palpable experiences of uncertainty about what type of outcome could be expected. This fluctuating uncertainty destabilised Thomas's 'horizon of possibilities' that seemingly made it easier for him to continue to hold hopes (as desire) that an operation (and therefore a cure) might one day be possible.

Tensions pertaining to the different aspects of future expectations and hopes thus involved struggling to reconcile 'hopes as desires' with more 'realistic' 'hopes as expectations', living in between these modest and more elevated hopes, as well as existing amidst uncertainty regarding what one hoped for – to be cured, to live longer with the illness itself or to have quality of life? In this sense hopes sat, often rather awkwardly, alongside anxieties or concerns of less optimal potentialities or even death. Perhaps more accurately, we might say that the uneasy combining of negative, realistic or modest and more bold or highly positive imagined outcomes for the future is central to what it means to hope.

Implicit versus specific hopes: tensions concerning 'taken-for-grantedness'

The previous sections have shown how considerations of futures and the hopes that lie therein were bound up with tensions within participants' narratives. One further set of tensions apparent within the interview data related to the relative specificity of hopes or future considerations. Time periods in the future, for example, could be delineated in a more explicit and detailed manner (a concert date, an 80th birthday, for example) yet above we have also seen references to 'the short-term' or 'the future' that remained somewhat more ambiguous.

Similarly participants sometimes expressed clearly *what* they were hoping for: treatment elongating their life, possible shrinkage of the tumour or, in very few instances, a cure. However as the following excerpt shows, this sense of 'specificity' was often couched alongside aspects of ambiguity:

> *I: What hopes do you still have?*
>
> *Daan: Well, hope. That I will be cured. Yeah. But eh, yeah.*
>
> *I: Do you think that you can be cured? Or that something will be discovered within a couple of years?*
>
> *Daan: There is something new all the time, hey. So yeah. But as long as it [the tumour] remains calm, that is what I hope. If it can't be changed, then yeah.*
>
> *[…]*
>
> *Every so often you hear about a new invention, and yeah, the Netherlands is advanced in that area. So that hope is there, yes, absolutely.*

Daan was initially rather explicit regarding his hoping to be cured but, when pushed further about progress within a specific time period, he pointed out that this was possible before readjusting to a more modest hope of a 'calm tumour'. Seemingly, combining a more distant hope (cure) *and* a specific time period involved a position that was too explicit (and thus vulnerable) in its hopefulness. He seemingly eased this tension by adjusting his hopes, while he continued to affirm more general possibilities linked to the national context of cancer research.

In a similar sense Thijs described a convoluted mix of more explicit and more ambiguous notions of hope:

> *Thijs: Yes. And who knows what happens within two or three years. So yeah, that is really what my hope is aimed at, that something will happen during that time. […] Hope is something that*

you, you know, you hope that you live for a long time, you hope your illness will be cured. I hope that. But it has been clearly stated that this is a disease that cannot be cured. Only when you can be operated on, then it is a different story. And ehm, yeah, but other than that you cannot have hope. The only hope is that they will eventually, eh, because my oncologist mentioned that after the summer, at the end of the year, another medication becomes available. And ehm, I don't know if that is still being tested, that might be the case, but then there will be another trial. Well, you know, you have to wait and see, you never know. Sometimes something happens, well, you can focus your hope on that. I think everybody who is sick does that. That you hope that a cure will be found, or that you are the one who can be operated upon. That is a hope I do have.

Here Thijs moved between very clear and specific (high) hopes - regarding living for a long time and being cured - and much more vague notions that 'something will happen' or 'you have to wait and see, you never know'. Although the implication was that this 'something' would be connected to trials and medical research, in some parts of the excerpt above uncertainty was heightened through implicit and undetailed remarks, whereas elsewhere the description of hopes contained more explicit specifics of what was hoped for.

The experience of living with hopes over time could generate multiple more or less direct meanings for those hoping. Above we saw that Lucas's experience at an out-patient appointment rendered the remoteness of his hopes problematically explicit, following new test results. In contrast, Eva and her daughter recounted how a rather modest, mundane yet quite specific hope of becoming more mobile came to be considered as something miraculous – which in turn was described as generating new more nebulous hopes:

Daughter: …Then you said 'I hope that I can just get to walk again'. Then you did it, and then you walked again.

Eva: Yes, and then you have to think this was just a miracle, that it was all possible again, see. Because, yes, you just leave it up to fate, you can't arrange it the way you would want it to.

I: Did your religious faith play a role? That you consider things that way?

Eva: Yes. Yes, I think so.

Here the realisation of one rather specific hope (walking) facilitated further hopes which related more broadly to 'all' being 'possible', alongside the impossibility of 'arranging' a specific neat future outcome. This latter generation of meaning regarding a more general new hope, along with the experience of the sacred amidst the profane, were embedded within the religious faith of this patient. Here again we see the salience of a broader lifeworld, shaped by the social and belief structures of the patient, laying the foundation for inferences through which hope was actively constructed. The construction of hope within this lifeworld involved both conscious reflection on being able to walk in light of more taken-for-granted structures of belief and meaning – deriving a more general hope from more specific ones. In turn we might infer that this more generalised hope (Wiles et al., 2008), embedded within faith, facilitated other more specific hopes that Eva mentioned elsewhere in her interview – making the tensions around these latter hopes easier to bear.

Discussion and Conclusion

This latter example, indicating the complexity and multidimensionality (Simpson, 2004) of experiences of hoping, offers insights into the difficulty of neatly conceptualising hope. More abstract and 'formal' definitions have been evaluated as weak and vague in reflecting lived experiences of hope (Crapanzano, 2003; Simpson, 2004:430) and indeed there is a case for 'cleansing' the conceptual apparatus through interrogating the theoretical in light of empirical studies of 'in situ' experiences of hope (Crapanzano, 2003; Simpson, 2004:430; Elliott and Olver, 2007). Taking our departure from the tensions that emerged more inductively within our analysis, though developing our understandings through a more abductive consideration of our data in light of theoretical literature (particularly that which considers hope in relation to

related processes – eg Zinn, 2008), we have developed a post-formal (Lomranz and Benyamini, 2009) analysis of hope. This approach emphasises attentiveness to the empirical messiness of hope, especially various distinct yet interwoven tensions which are borne amidst lived experiences of hoping.

As apparent in the data presented above, tensions in considerations between more short-term and more distant futures were often deeply bound up with both the extent to which more positive possibilities or realistic 'expectations' (Wiles et al., 2008) were envisaged and the relative explicitness or taken-for-grantedness of these possible outcomes. More distant and vague possibilities, in their intangibility, seemingly facilitated the extent to which these could be imagined as positive (even cures were envisaged). The more remote and ambiguous ontologies of the distant future, by their very uncertainty, were rendered more pliable within the imaginations and desires of the advanced-cancer patients in our study. These more tentative possibilities often stood in tension with what was seen as viable in the shorter-term. For whereas the shorter-term was often considered through a lens of what was 'likely', as limited by the imposition of 'truth' by clinicians ('remaining realistic'), the greater uncertainty of the distant future granted more freedom to resist (Brown, 2005). Bearing such dissonances (Lomranz and Benyamini 2009) would seem intrinsic to the very nature and vulnerability of what it means to hope (as initially touched upon by Simpson, 2004), suggesting that hoping may always be uneasy.

These core findings contribute to the more sociological and anthropological literature by extending the study of institutional and interactional processes involving hopes into the lived experiences of hoping. We have noted how more general cultural notions involving biomedicine and clinical trials and, more explicitly, the interactions of patients with professionals and others within their social sphere have shaped the lifeworlds in which hope was enacted. In conceptualising the shaping of lifeworlds, in contrast to those studies (eg Good 2001) which suggest hope is more directly driven by wider social processes, we have remained attentive to

the agency of the hoper in reimagining or bracketing off the 'expected' or 'likely' amidst the imposed futures of professionals and others. The ongoing construction of lifeworlds, in structuring assumptions about future-time and plausible ontologies therein, undoubtedly influences hope but is not determining.

Our data further indicated that interactions within the 'biomedical embrace' (Good, 2001) could facilitate hope while also shattering futures. The uncertainty emphasised in interactions with professionals, alongside the biographical disruption due to advanced-cancer diagnoses, undermined the taken-for-granted 'reality' of everyday life (Habermas 1987:400). This destabilising of lifeworlds assisted the agency of patients in reworking these – stretching back future horizons and reimagining hopes. Yet these new lifeworlds remained unstable and insecure, entailing ongoing experiences of precariousness (Giddens, 1991), especially following interactions with professionals.

In drawing attention to the tensions and fragility emerging through processes around hoping, we have also sought to contribute to the more applied literature focused on definitional issues. The nature of hoping, as embedded within lifeworlds, is inseparable from the social contexts of hopers. We have suggested that tensions should be more explicit within, and portrayed as characteristic of, depictions of hope. The 'aintegration' qualities of hoping (Lomranz and Benyamini, 2009) become more apparent when considering hope alongside other approaches to vulnerability and uncertainty such as risk and trust (Zinn, 2008). Prior studies have noted the 'alternation' between hope and despair, or hope and hopelessness, within life-threatening illness experiences (eg Kylmä et al., 2001). The post-formal analysis of our data presented above points instead to the simultaneous experience of despair and anxiety alongside – or, more accurately, as part of – hope. To bear the incoherence and disturbance of different temporalities, possibilities of both positive and negative outcomes, and ambiguities (Lomranz and Benyamini, 2009:7) was very much part of hoping for the participants in our study. This was apparent from

the frequency with which statements such as 'I have no future' were preceded or succeeded by references to positive future possibilities.

There are of course important specificities of our study, in terms of the severity of diagnosis, trial involvement, alongside the format of interviews and observations, which may have given us a particular understanding of hope and its tensions which would be less apparent in other research contexts; e.g. regularly following up patients over longer time-periods. Chronic illness contexts (Williams, 2001) or those living without a diagnosis but 'at risk' (Alaszewski et al., 2006) may experience hope in rather different ways. While our data revealed a tension between hope as mundane perseverance and hope as reflexive-existential tool (Zigon, 2009), other healthcare contexts may involve a different weighting towards the former. The heightened vulnerability and uncertainty experienced by the advanced-cancer patients in our study arguably made more explicit or pronounced some of these tensions that are important to understanding experiences of hope. Future research into contexts where tensions are less explicit could raise methodological difficulties, though the use of a post-formal approach as a sensitising framework may nevertheless assist in analysing the social dynamics and nature of hoping.

Notes

[1] These authors point towards contemporary physics and various theoretical developments therein; e.g. pertaining to relativity, chaos, and quantum theories involving one sub-atomic particle simultaneously existing in two places.

[2] Lucas specifically mentioned at the start of the interview that he wanted his wife present during the conversation. He explained that she was his emotional counterpart, and that she was better in expressing certain views, feelings and emotions that they both had. Therefore, the sentiments expressed by his wife in relation to hope can be seen as an expression of both his wife's view on hope, as well as Lucas's.

[3] Describing the fluctuations of hope over time also raises the problem of eliciting narratives specific to the day of the interview.

References

Alaszewski A Alaszewski H and Potter J (2006) Risk, uncertainty and life threatening trauma: analysing stroke survivor's accounts of life after stroke. *Forum Qualitative Social Research* 7(1):18

Barbalet J (2009) A characterisation of trust, and its consequences. *Theory and Society* 38(4):367–82.

Bourdieu P (1999) *The Weight of the World: social suffering in contemporary society*. Redwood City:Stanford University Press

Broom A and Tovey P (2008) *Therapeutic Pluralism: exploring experiences of cancer patients and professionals*. London:Routledge.

Brown N (2005) Shifting Tenses: Reconnecting Regimes of Truth and Hope. *Configurations* 13 (3): 331 – 355

Brown P Alaszewski A Swift T and Nordin A (2011) Actions speak louder than words: the embodiment of trust in gynae-oncology. *Sociology of Health and Illness* 33(2):280-295.

Brown P and de Graaf S. (2013) Considering a future which may not exist: the construction of time and expectations amidst advanced cancer. *Health, Risk and Society* 15(6):543-60.

Crapanzano V (2003) Reflections on hope as a category of social and psychological analysis. *Cultural Anthropology* 18:3-32

Eliott J and Olver I (2007) Hope and hoping in the talk of dying cancer patients. *Social Science and Medicine*64:138-49.

Ezzy D (1998) Theorising narrative identity: symbolic interactionism and hermeneutics. *Sociological Quarterly* 39:239-52.

Giddens A (1991) *Modernity and Self-Identity: Self and Society in a Late-Modern Age*. Cambridge: Polity

Good MJD Good B Schaffer C Lind S (1990) American oncology and the discourse on hope. *Culture, Medicine and Psychiatry* 14:59-79.

Good MJD (2001) The biotechnical embrace. *Culture, Medicine and Psychiatry* 25(4):395-410.

Gordon EJ and Daugherty CK 2003 Hitting You Over The Head: Oncologists Disclosure of Prognosis to Advanced Cancer Patients. *Bioethics*17(2):142–168

Gysels M Shipman C Higginson I (2008) Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics* 9:7

Habermas, J. (1987*) Theory of Communicative Action*: vol. II. Cambridge: Polity.

Kierkegaard S (1957) *Concept of dread*. Princeton: Princeton University Press

Kylmä J Vehviläinen-Julkunen K and Lähdevirta J (2001) Hope, despair and hopelessness in living with HIV/AIDS: a grounded theory study. *Journal of Advanced Nursing* 33(6):764-775

Lam A 2000 Tacit knowledge, organizational learning and societal institutions – an integrated framework. *Organization Studies* 21:487–513.

Lerner, B. (2001) *The Breast Cancer Wars: Fear, hope and the pursuit of a cure in Twentieth-Century American*. Oxford: Oxford University Press.

Lomranz and Benyamini (2009) *Aintegration in Management of Personal and Work-Organizational Conflicting Situations in Modern Society.* Paper presented at conference: SCARR: Managing the Social Impacts of Change from a Risk Perspective. Beijing Normal University;15-17April.

Miller M (2000) Phase 1 cancer trials: a collusion of misunderstanding. *Hastings Center Report* 30(4):34-43.

Neuman W 2000 *Social research methods: qualitative and quantitative approaches*. Boston, MA: Allyn and Bacon

Novas, C. (2006) The political economy of hope: patients organisations, science and biovalue. *Biosocieties* 1(3):289-305.

Ricoeur P (1990)Between hermeneutics and semiotics. *International Journal for the Semiotics of Law* 3:115-132.

Schutz A (1972) *The phenomenology of the social world*. Evanston: Northwestern University Press

Schutz, A. (1973) *The Structures of the Life-world: vol.1*. Evanston: Northwestern University Press.

Seale, C. (2002) Cancer heroics: a study of news reports with particular reference to gender. *Sociology*36:107-26.

Simpson C (2004) When hope makes us vulnerable: a discussion of patient–healthcare provider interactions in the context of hope. *Bioethics*, 18 (5), 428–447

Sinding, C., Hudak, P., Wiernikowski, J., Aronson, J. et al. (2010) ,I like to be an informed person but…negotiating responsibility for treatment decisions in cancer care. *Social Science and Medicine*,71,6,1094-1101.

Smith, J., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, method and research*. London:Sage

Sontag S (1978) *Illness as Metaphor*. London: Penguin.

van Dantzig A & de Swaan A (1978) *Omgaan met angst in een kankerziekenhuis*[Coping with fear in a cancer hospital].Utrecht:Spectrum.

Wiles, R., Cott, B. and Gibson, C. (2008) Hope, expectations and recovery from illness: a narrative synthesis of qualitative research. *Journal of Advanced Nursing* 64(6):564-73.

Wilkinson I (2004) The problem of social suffering: the challenge to social science. *Health Sociology Review* 13:113-121.

Williams S (2001) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness* 22:40-67.

Zigon J (2009) Hope dies last: Two aspects of hope in contemporary Moscow. *Anthropological Theory* 9:253-71.

Zinn, J. 2008 Heading into the unknown: Everyday strategies for managing risk and uncertainty. *Health, Risk & Society* 10 (5):439-450.

Table 1: Characteristics of Cancer Trials

Cancer	Phase	Randomised	Placebo	Arms
Pancreas	2	Yes	Yes	Group A: standard care + trial medication Group B: standard care + placebo
Multiple Myeloma (Bone marrow)	3	Yes	No	Group A: standard care Group B: standard care + trial medication
Colon	3	Yes	No	Both groups receive standard care + trial medication at first. Group A: Stop of treatment Group B: Continuation of treatment with different doses
Multiple Myeloma (Bone marrow)	3	Yes	No	Both groups receive standard care, but are injected in different ways
Kidney	3	Yes	No	Both groups receive standard care, but medication in each group is given in different order and doses

Table 2 – Basic patient characteristics

Participant pseudonyms	Partner or family member present	Age bracket
Ruben	No	40-49
Sanne	No	50-59
Tim	Yes: Wife	50-59
Gijs	Yes: Wife	60-69
Thijs	No	60-69
Thomas	No	60-69
Anna	No	60-69
Daan	No	60-69
Lars	Yes: Son	60-69
Roos	Yes: Daughter	60-69
Eva	Yes: Daughter	70-79
Lucas	Yes: Wife	70-79
Marcel	No	70-79