

Disruption, discontinuity and a licence to live: Responding to cancer diagnoses

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Abstract

Although a diagnosis of a life-limiting cancer is likely to evoke emotions, such as fear, panic and anxiety, for some people it can also provide an opportunity to live life differently. This article is based on research undertaken in Aotearoa New Zealand on the topic of exceptional cancer trajectories. Eighty-one participants who had been identified as living with a cancer diagnosis longer than clinically expected were interviewed, along with 25 people identified by some of the participants as supporters in their journey. For some participants the diagnosis provided the opportunity to rethink their lives, to undertake lifestyle and consumption changes, to be culturally adventurous, to take up new skills, to quit work and to change relationships with others. The concepts of biographical disruption and posttraumatic growth are considered in relation to these accounts, and it is argued that the event of a cancer diagnosis can give license for people to breach social norms.

KEYWORDS

biographical disruption, breaching norms, cancer survivorship, posttraumatic growth

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INTRODUCTION

A diagnosis of cancer can have a profound impact. Depending on the prognosis, or the understanding of a prognosis, a diagnosis can evoke a range of emotions, such as fear, panic, anxiety, depression and suffering (Salès-Wuillemin et al., 2023). It is then, disrupting.

For those who have lived with a diagnosis of cancer for a long time the disease can be considered in light of sociological understandings of chronic illness, such as Mike Bury's concept of biographical disruption (Bury, 1982). Bury initially developed the concept of biographical disruption through research with people diagnosed with rheumatoid arthritis (Bury, 1982). He drew on Giddens's (1979) term 'critical situation', where day-to-day situations are radically disturbed. Bury argued that chronic illness "is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury, 1982, p. 169). Disruption included the "breaching of common-sense boundaries" (ibid) and the disruption of taken for granted assumptions, the disruption of explanatory systems and a "fundamental re-thinking of the person's biography and self-concept" (Bury, 1982). New resources are mobilised in the face of the disruption to everyday life, and normal rules of social reciprocity are disrupted because of growing dependence on others. The social legitimacy provided by a disease diagnosis can be the basis of deviant behaviour (Bury, 1982), such as drawing on Parsons' concept of the sick role and not fulfilling normal social obligations (Parsons, 1958). In resisting a deviant status, participants attempted to "normalise in the face of disruption" (Bury, 1982). The term normalisation has been used to describe a form of coping where illness and treatment are considered 'normal' (Williams, 2000). Williams notes that biographical disruption is not an inevitable outcome for those with chronic illness, for example, some people may anticipate or expect chronic illness as it may indeed align with understood norms and expectations for disadvantaged segments of society, or 'normal' expectations of ageing (Williams, 2000). Williams notes that chronic illness is life limiting, but a cancer diagnosis can provide an extra dimension to that idea by forecasting a time limit to life.

Biographical disruption as a concept has been applied to understand the experiences of those with a cancer diagnosis. For example, in a study of women in Thailand diagnosed with breast cancer the diagnosis led to a sense of chaos followed by an acceptance of fate aided by drawing on Buddhist beliefs (Liamputtong & Suwankhong, 2015), whereas a UK study of women with breast cancer diagnoses noted that embodied changes following treatment denied the possibility of a return to 'normal' identity, and a new normal required a continual renegotiation of identity (Trusson et al., 2016). Previous use of this concept in cancer diagnoses has tended to emphasise the negative impact of disruption and efforts to re-establish normality, including research on prostate cancer (Schultze et al., 2020). Research studies on cancer patients with a poor prognosis highlight the continued disrupted trajectory and on-going concerns such as a fear of recurrence (Balmer et al., 2015).

Disruption for those given a life limiting or terminal diagnosis can be exceptional. But it is not always exceptionally negative. What might lie beyond the negative and is it worthwhile highlighting that? Only a few sociological research studies have explored the diversity of outcomes, positive, negative and otherwise, following a cancer diagnosis. An early exploration of illness having potential benefits is that of Herzlich (1973) who refers to illness as a destroyer, a liberator or an occupation. Herzlich's 80 participants were not necessarily ill, so not necessarily speaking from experience, but for those who thought that illness could be a liberator it was a situation in which forms of role deviance could be accepted, where one could be idle and enjoy

having time away from expected activities. Illness was articulated as “a defence against the demands of society” (Herzlich, 1973). Facing death and experiencing pain provided the possibility of someone developing an “exceptional personality”, experiencing what others have not (Herzlich, 1973). Frank describes three broad illness stories that people tell: restitution, chaos and quest. In the quest story the darkness of illness can be transformative, such as leading to the development of wisdom and compassion (Frank, 2013). In more mundane terms, biographical disruption from cancer can lead to a reassessment of priorities, especially with those that have the financial means to do so. This can lead to changing jobs in order to achieve something more positive in life, and as such revising identities, or reducing work hours to have more pleasurable experiences, such as being with grandchildren (Trusson et al., 2021).

Cancer has been argued to be beneficial and empowering when those diagnosed could either establish a sense of control or relinquish control and accept change (Avery et al., 2023). Clearly this capacity varies by different kinds of cancer, especially those with rapid onset compared to those that are slowly developing. Attitudes may change. In their study of health professionals in Turkey who had a history of disease-based trauma, Izgüden and Erdem found a change in priorities for some participants, including taking a “me first” attitude and reducing work commitments, and also other changes, such as family ties becoming stronger, having greater empathy with their patients and seeing the trauma as a lesson that brought them closer to God (İzgüden & Erdem, 2022).

In Broom and Kenny’s studies of cancer survivors they note that for some participants the disruption in life’s trajectory created by a life-limiting cancer diagnosis can be a “welcome opportunity for discontinuity”. They cite the example of Richard who, following the diagnosis, travelled overseas “which otherwise would have seemed too ‘self-indulgent’ and not ‘sensible’” (Broom & Kenny, 2021, p. 89). They cite another example of someone spending more time at home “enjoying that time” despite the circumstances (Broom & Kenny, 2021). Schultz et al. (2020) note that for one participant the sexual dysfunction that occurred with prostate cancer led to a positive rebalancing of sexuality with his partner. In a study of women with stage 3 ovarian cancer Thompson (2007, p. 346) suggests that although experiencing existential disruption:

a catastrophic illness...may lead to a subjective sense of personality change, of deepening ties to others and the transcendent, as well as an ability to pay exquisite attention to the nuances of daily life. These changes were reported as positive for the participants.

There are allied notions emergent in the psychotherapeutic and psychological literature. Posttraumatic growth (PTG) is a concept that has been deployed, particularly in quantitative psychology studies, to consider positive responses to disease and other traumatic events. PTG is conceptualised in psychological terms as a positive change following from the challenging life circumstance of trauma, and in the case of cancer research could include better personal relationships, intensified spirituality and changes in priorities (Danhauer et al., 2013; Menger et al., 2021). Growth from this perspective requires re-establishing a sense of the world (Menger et al., 2021). This could include coming to a better appreciation of life. Effort has gone into identifying, without much consensus, what variables might foster PTG (Menger et al., 2020). In contrast, we consider mechanisms by which change may occur, and in particular the license to breach contemporary social norms that may be given to people diagnosed with cancer (Powroznik et al., 2018).

The concept of PTG and other discourses exhorting those with cancer to be positive has come in for criticism from scholars outside of psychology (Bell, 2010; Steinberg, 2015). Bell (2010) challenges the moral value of cancer survival strategies that are entwined with imperatives to diet, exercise and to have a positive mindset (Bell, 2010), and the potential of a posttraumatic growth framing to pathologise those who do not seek growth (Bell, 2012). Steinberg critiques the “neoliberal body-reflexive ethic that infused the representational field of cancer” (Steinberg, 2015), arguing that, among other matters, it denies mourning, loss and death.

The aim of our study was to explore the experiences of those who had lived longer than expected following a diagnosis of cancer. For this article our objective is to consider the ways in which a cancer diagnosis can give license to people to change their lives.

RESEARCH DESIGN

This article explores issues of positive change following a cancer diagnosis using data from participants who had survived cancer longer than expected. Ethical approval for this research study was accessed from the (Deleted for anonymising purposes). Although discussions of cancer diagnoses and their sequelae have the potential to evoke strong emotional responses, and tears were indeed shed in some interviews, all participants were made fully aware of what would be covered in the interviews prior to consent and participants frequently expressed gratitude to the researchers for having the opportunity to talk about their experiences. Participants (81) were obtained through the Cancer Registry (57), and through networks or responses to media publicity (24). The Cancer Registry provided contact details for lung cancer registrations where the extent of disease was distant (that is, distant metastases) and the patient had survived for 5 years or longer, those with 5 years or longer survival with cancer of the oesophagus, pancreas, or with sarcoma or liposarcoma where the extent of disease was distant, and those with 5 years or longer survival with brain cancer, liver cancer and endometrial cancers, for the latter two where the extent of disease was distant. Letters were sent out to potential research participants and if interest was expressed information sheets and consent forms were provided.

Diagnosis information was obtained from participants identified through our own networks or who responded to information about the research study disseminated through the media (primarily local community newspapers), and our clinical advisor (ED) assessed if the survival seemed exceptional, in which case they were invited to participate in the study. There is no agreed definition on how to measure the exceptional, and our interest was on the trajectory rather than survival per se, but surviving longer than five years in the face of a predicted survival rate of less than 20% has been used by researchers (Hök et al., 2009). For some of the cancers in this study the 5-year survival rate is less than 20%.

Eighty-one participants were interviewed from 2020 to 2022 from throughout Aotearoa New Zealand. Forty-six were interviewed in person, but in response to COVID restrictions, seven were interviewed via video-links and 28 by phone, with one participant with hearing difficulties preferring to respond via email. Three authors (KC, KD and RE) conducted the majority of the interviews with a Māori research fellow conducting interviews with the majority of Māori participants under the supervision of CC (also Māori). Those who collected the data are from different disciplines (sociology, social psychology, Māori health research, health promotion), and across the research team, members have different experience of the health system,

including surgical oncology and health promotion. Collectively, we engaged in a process that has been called artful contamination, where individual insights are productively entangled, challenged and transformed (Zuiderent-Jerak, 2016).

Narrative interviews were used to obtain participants' accounts of cancer survival with this approach deemed appropriate to obtain time-based experiences (Reissman, 2008). Participants were asked to tell the story of their cancer journeys in conjunction with a timeline to identify major events, turning points, disruptions, significant changes and so on (Patterson et al., 2012). Participants were asked what led up to their diagnosis, what treatment occurred, what part they played in the decision-making, what if any non-conventional or non-medical approaches they took, who helped in the process, what they would say to someone who was given a cancer diagnosis, and what has helped in their trajectory? They were not specifically asked if they considered cancer as having positive aspects, this emerged from their accounts.

From the 81 participants in the first phase of this research study 14 were followed up to ask if they would be willing to identify people who supported them in their cancer journey whom we could ask to participate in the research. Support people identified included family, friends, and health professionals, both orthodox and alternative. Twenty-five supporters were interviewed by phone or via Zoom and asked about their involvement in the participant's cancer journey and their understanding of the participant's survival, and relevant talk from these interviews has been included.

Audio-recordings were transcribed and checked by all interviewers. After the transcriptions had been read and themes identified the research team came together to discuss initial avenues of interest. For this article the first author read through all the transcripts identifying text related to opportunities and benefits following a cancer diagnosis. The data was then considered in relation to relevant concepts, identifying conceptual orientations that would provide insight into participant's accounts, with a particular focus on the disruption of cancer and its affordances. All names given to participants are pseudonyms.

FINDINGS

Of the 81 participants, 36 were male and 45 were female, 23 were Māori and 58 were non-Māori, and ages ranged from 19 to 97 years. Time since first diagnosis ranged from 4 to 32 years. The most common primary diagnoses were related to the brain (28), lung (16), breast (10) and pancreas (7), with a range of other cancers including mesothelioma, melanoma and bowel. Of the 81 participants 26 explicitly expressed the view, unsolicited, that cancer had some positive impact on their lives, although by no means downplaying the negative impacts it could have as well. Many others implied benefits.

We have organised the findings in relation to Bury's dimensions of biographical disruption. First, illness unsettles the body, social roles and the social world through "the disruption of taken-for-granted assumptions and behaviours" (Bury, 1982). Second, chronic illness disrupts self-identity to such an extent that a fundamental rethinking of the individual's biography and their self-concepts is involved (Charmaz, 1995). Third, the way in which individuals respond to disruption involves "the mobilisation of resources in facing an altered situation" (Bury, 1982, p. 169). In this article we do not focus on the unsettling dimension, but by no means do we wish to minimise that. In the following the rethinking dimension is discussed in relation to changes in perspective. The responding dimension we consider relates to lifestyle and consumption changes, new skills and activities, job and location changes and relationship changes. To some

extent rethinking is a response, so these dimensions should be treated as a heuristic rather than as tightly defined.

Rethinking and change

Many participants talked in positive language about the impact of a cancer diagnosis on their lives and the ways in which it could give them license to be different and change. Participants might focus on bringing more joy into their lives and being willing to breach accepted social norms. Some talked of gaining new strength and for some the 'event' of a terminal diagnosis could profoundly change everyday life.

Participants made statements like "it's a privilege actually" (Jacob), "we call it my friend" (Michael), "the most amazing opportunity happened to me" (Olivia), "I'm thankful for it" (Tokoeka), "it gave me a sense of relief" (Tūi). However, getting to a positive place could take time. Christine's sister, who is also a practicing therapist, captures this in her talk of visiting a cancer treatment centre in the States for another cancer in her family when she was told 'With this comes gifts'. Christine's sister "could have easily just bopped her on the nose", but now she understands that comments differently as the cancer:

had changed our entire life, this cancer. But it hadn't necessarily changed it all for the worse, you know, because the family became closer. We were learning all these things about diet, and ... everything was a learning. It wasn't all negative.

Many participants thought about life in a different way following diagnosis, aligning with Frank's (2013) quest narrative. Sophie takes the view that "life is short" and that the diagnosis of cancer can be "a positive experience as in don't sweat the small stuff, enjoy yourself, it's not necessarily a death sentence". After Lily was told that she was dying "you don't get jealous of other people or what you own or any of that stuff. You don't really get so judgemental like you used to be" Olivia states:

I've had cancer and it's my buddy ... I don't wish cancer upon anyone but I'm a much better person having cancer in my life. I know it may suck but it sounds really weird, but I've changed so much as a person, and I love the way that I am now. I let things go quicker, I have the ability to just laugh and be kind.

For these participants cancer had provided the opportunity to live life differently, to learn new things, enjoy themselves more and to change as a person. For Kererū, learning "not to be a stress buddy" had the practical outcome of her "going down from two antidepressants a day to one". The participants gave themselves license to breach norms of behaviour, to be more compassionate to themselves and others, and to develop wisdom.

Being kind to oneself was a commonly noted change in perspective. Olivia asked herself "How are you going to live this life?" and answered it with "I'm going to learn to receive. Just learning to receive with gratitude and not having to reciprocate with that particular person". She provides examples of people dropping off food for her, but she did not feel the need to reciprocate but just be thankful.

Bury (1982) notes that for his participants the disruption of the capacity to reciprocate can have a negative impact on people's capacity to mobilise resources, but for Olivia the cancer

diagnosis has given her license to not have to think about rules of reciprocity, but just receive what is offered. Hihi gives herself license to do what is best for her, using her own embodied responses to determine how she will respond to others: “So now, if I hear something, someone asks me something, and if my body stress is like, tenses up, that’s a no”. Ella gave herself license to be less busy and not “stressed all the time”. Participants here are breaching social norms of reciprocity and resisting social pressures to participate or conform to a work ethic.

Some participants, such as Benjamin, diagnosed with terminal brain cancer 16 years ago, expressed the view that having cancer had built up their resilience. Three years ago he had an accident and lost an eye but “it didn’t really faze me at all. I think it’s just part of what I’ve been through”. Such sentiment aligns with research on “stress toughening” where it is argued that adverse experiences can assist people in dealing with current problems (Dooley et al., 2017). Benjamin’s view that the trauma of losing an eye is “just part of what I’ve been through” speaks to a sense of continuity post-cancer diagnosis, or what Williams (2000) refers to as biographical reinforcement. For Rebecca this biographical reinforcement had a spiritual or religious dimension. Rebecca, diagnosed with undifferentiated sarcoma seven years ago when she was 13, “got really into my (Catholic) faith” and that “helped with my attitude of just like, keep going and just like, block everything out.” Tokoeka had fibrillary astrocytoma diagnosed 8 years ago when she was 20:

I mean, I’m thankful for it. Now. I wouldn’t be in the job I’m doing. I wouldn’t be where I am if it hadn’t have happened, because it’s made me very focused and driven. But definitely took away... those young carefree years, for sure.

For Tokoeka her response to cancer is to push herself acknowledging the loss of carefree years, but obtaining a change of state that has provided new opportunities for her.

Susan has breast cancer with metastases to lungs, bones and brain and had been given 3 months to live. Susan’s GP considers that her survival 5 years later has been exceptional, and, in keeping with the quest narrative, Susan’s GP suggests that cancer can be a challenge that can “help you grow to develop as a human being...it really means what does it take to live”.

For others the experience of cancer gave them the license to change the way they experienced the world. It could foster gratitude and a focus on joy and the now, expressed by Greta as “living in the moment, like taking each day, trying to make the most of it”. For Mia, who had been given a 1-year prognosis the world got “greener and smells better and the sky is bluer”. The “blessing” of being told she is going to die produced a reaction in Mia of living more intensely.

From these narratives we can consider the diagnosis of a life-limiting illness as an ‘event’. Jay (2013), referencing historical events (he focuses his discussion on events in France in May 1968), argues that an event is a pivotal moment in a meaningful story, or that it may be so impactful that “no coherent story could contain it”. The witnessable event can provide a challenge to the “system” as it is incommensurable with it, and a disruption to it. The biographical disruption of a cancer diagnosis may, for some, be analogous to an event in this sense. For Jay the event troubles dominant structures, and for an individual (or the wider circle of friends and family) the cancer diagnosis may trouble dominant norms, expectations and sense of obligation. For Jay the event is “an unusual and profound thing that opened up a tear in the fabric of everyday or mundane life” (Jay, 2013, p. 14). The torn fabric, rather than being repaired, is reworked as participants live life differently.

Responding

Participants took many different kinds of actions in response to a cancer diagnosis. Lifestyle changes were common and could provide a sense of control and support, seeking out alternative ways of living following a diagnosis. Others made an opportunity of the circumstance to change their jobs or quit work altogether. Some took the chance to learn new things, either for themselves or for others, and this could initiate a journey of transformation.

Lifestyle changes were a common response for many participants, as reflected in other literature (Beeken et al., 2016; Bell, 2010). For some this had the sense of being imposed or demanded, but for some it was embraced. Bernadette declared that “I changed my lifestyle”. Bernadette did a lot of walking, cut back on meat and joined the gym. Cutting down on sugar was, however, imposed following surgical interventions to her pancreas to treat insulinoma. Esther, in addition to moving to a new location, took up yoga “and I just love it”. Michael, who has survived 10 years with a mesothelioma diagnosis, made many changes to his lifestyle to avoid chemicals and processed foods as well as trying a range of remedies and supplements. These kinds of changes were common, if not always sustained. But they could signify something more—lifestyle changes being part of an attitude towards the cancer and what can be done about it—that some sense of control could be manifested. Cancer patients and the issue of control has been extensively researched (see for example Avery et al., 2023). This is well articulated by a friend of Andrea’s who happened to be a health-care specialist, and was sceptical about dietary changes being “protective against advancing disease” and was concerned that people “blamed themselves because they didn’t eat enough raw broccoli”, but for Andrea he stated:

it was her way of taking control of the situation... she has now got the mindset that whatever she can control she will control. And that is what has made her feel good, I think.

An approach of controlling what one can, and actively responding to the situation can be related to Frank’s (2013) quest narrative, where there is a search for alternative ways of being ill. We see this kind of quest throughout this section. Other practical changes included elements of consumption, such as refurnishing the home or travelling abroad.

Several participants had changed jobs or quit work following their diagnosis. Deborah made “life changes”. Her work environment was “a bit toxic” so Deborah resigned and took up related work so “I could just do what I really liked doing”. Hector gave up his job because of cancer but also because “I was getting sick of the rules and regulations in real estate”. Liam resigned so that he could “use the next 2 years” he was given to live as best as he could. Because of the time limit given “I should use it well and I should relate, enjoy, work closely, all those sort of things, with my immediate family, with my sons, with my wife, with my friends and I didn’t find that difficult”.

Michael said that at one stage he called his diagnosed mesothelioma “my friend. (laughter)” as he quit his 10-hour a day job that he found stressful. Esther was given a poor prognosis after being diagnosed with lung cancer 7 years ago and so moved to set up a home with her son to build memories, and she now loves “living here”.

A number of participants learned new skills and participated in new activities following their diagnosis. Bernadette learnt Reiki following treatment for insulinoma. She saw this as an “almost spiritual thing”. The inspiration to learn Reiki was a post-operative experience when

Bernadette had intense referred pain and while in hospital a nurse, who had done some “hand healing” training, worked on Bernadette and reduced the pain even though pain medications had failed to do so. But taking up art at 65 had even more of an impact on her as it “was one of my best probably healing thing”.

Liam, who had been given 2 years to live, took up carving, so leaving a creative legacy to his family:

I think what kicked it off was knowing that, at some stage, I’m going to die... I just had this urge to leave something behind and it revolved round the only grand-daughter...something for her...and I look at things differently, I look at people differently. It’s a huge reward, just wouldn’t have happened otherwise.

Kōkako was diagnosed with a glioblastoma grade 4 brain tumour 9 years ago which, after treatment, returned 4 years later and was given 2 months to live. Kōkako embraced rongoā (indigenous Māori traditional healing) approaches to healing, including its spiritual side and now loves her “journey” and “this is what I was supposed to do.” Kōkako is expressing a journey of transformation, an element of the quest narrative, where Kōkako has “been given something by the experience” (Frank, 2013, p. 118). Another participant who was told he had a 2-year life expectancy engaged in charity activities for cancer, using the “bad thing that’s happened” to foster an attitude of altruism and generosity.

For some participants responses to cancer established a new normal, where new homes were established, creative opportunities taken up, cultural perspectives reclaimed, jobs changed or left. A life limiting disease could, for some, be a means of resisting the demands of society (Herzlich, 1973).

Changes in relationships

Trusson and Pilnick (2017) note how relationships can change for women with breast cancer. Many of their participants experienced friends and relatives becoming more distant because they could not handle the situation, and other participants actively made choices about who they told about their cancer and what they told. In some cases, relations strengthened with partners, with one instance of a relationship ending because of a partner’s inappropriate reaction of hijacking his partner’s illness. Relationships changed in different ways following a cancer diagnosis for our participants, with many participants taking an active role in deciding what sort of relationships they wanted.

Jacob, who has lung cancer of 7 years with pelvic metastases, has prayed so that he can play with his, yet to be born, grandchildren. But Jacob also states that “it’s a privilege actually” as the cancer was a warning, so he spends more quality time with family: “at the end of the day, it’s actually a positive thing, because you got to realise that life is precious and therefore make the most of it, so it’s good”. For William having lung cancer has brought him closer to his partner and Luna has got closer to her Dad. Hector’s oldest son talks of how his father changed following a diagnosis of lung cancer: “when we were growing up, we were not a family of close contact and showing feelings” but now his father “doesn’t want to leave things unsaid, telling my brother and I how important we are and just a lot more obvious communication of affection.” Hector’s other son also notes that his father “enjoys time with the family and taking an

interest in what the grandkids are doing". His son has also changed, now visiting more regularly, and taking every second Friday off work to do so.

A different take on the importance of relationships can be seen in those who take the opportunity to be more selective in their friendships. Hihi, told a year before the interview that she had 12 months to live, "made a conscious decision not to be around people who are negative." The diagnosis of cancer has given Hihi license to be more selective about with whom she spends time. Andrea, who has melanoma, now walks, swims, does yoga and mindfulness meditation, and also uses some herbal preparations, takes a similar approach and just wants "to spend it with real people, or I'm happy enough on my own". Kererū has "cut a lot of my negative girlfriends out of my life" and is "really looking for awesome wāhine (women)". Tūi' who 12 years ago was given a 12-month life expectancy, now says how she feels rather than "bottling things up" as "I may not get another opportunity".

Brendan is a consultant physician and his experience of having cancer has had a positive impact on how he responds to patients. Brendan notes that his career "has helped me survive", in part in response to his knowledge of pathology and his connections in the health system, but "it's changed my attitude to fatal disease in patients in a positive sort of way". Brendan's comments echo those found in research studies on health professionals who have experienced traumatic disease (İzgüden & Erdem, 2022).

We acknowledge that the 'exceptional' trajectories of this sample also lean towards an emphasis on the more-than-negative aspects of the contours of cancer as an illness journey A GP who provided care to Susan sums this up:

A diagnosis of cancer strikes so much fear in people it is really important to have people out there to show people what is possible.

Susan's GP is referring to the possibilities in terms of treatment pathways and outcomes when a terminal diagnosis is given, but we can also consider the stories here as possibilities for people, possibilities that foreground the transformative potential.

Transforming and returning

In the following we focus on one participant, Beatrice, to bring out the complexity and ebb and flow of the license to breach social norms. Beatrice was only given 3 months to live following a diagnosis of adenocarcinoma of the lung. Beatrice's response was perhaps the most dramatic in terms of making immediate changes to her life circumstances, accentuating the transformative nature of the experience for her. Beatrice said "I mainly worked on my joy". She had to work on joy as "to actually feel joy, to actually love yourself is the hardest thing in the world" Beatrice had realised, once she had received the diagnosis, "that I had lost my joy", and that she "didn't want to be miserable for 3 months before I die".

She got rid of her possessions and moved out of her flat and quit her job. Beatrice's working situation was one she felt was a factor in her getting cancer. After her diagnosis Beatrice had asked herself "why has the cancer come to me". And: "I know exactly why and that was because of the job that I'd had I got very stressed about it". Beatrice worked with children but felt the way her employer operated was "evil, I don't use that word ever, but with them it was because they would make really bad decisions to disempower kids". In her effort to fight this situation

Beatrice was “suffering in the process...so I knew why I had got it, if you know what I mean, like because I’d been in this state of absolute frustration”. The cancer diagnosis gave Beatrice license to quit her job, and eventually to work on her recovery.

Before she died Beatrice wanted to return to her home country to say goodbye to family. Beatrice’s herbalist says:

but something happened in (her home country). And I think she saw her father again, there was resolution - she reconnected on a different level where she no longer felt isolated from that, and I think that was even part of her recovery.

As Beatrice did not die as expected she had to resort to relying on friends to stay with—but this had positive elements:

and then I sort of just lived at (friends) for about six months ... they had an Airbnb downstairs, so I left the Airbnb because they needed to earn the money... I didn’t have any money for rent... so I left and hit the road... I went and stayed with friends basically. Just giving them, you know, say 100 a week, and buy my own food or something. So, paying my way but not paying official rent... I would stay say for a month with a friend and then move. And it was good, because I kind of felt I was going around saying goodbye to them.

However, her change of circumstances to being a survivor was having consequences as Beatrice had moved from a situation where, without having to have employment, she could work on herself and her joy, but now she would have to try and return to work again:

I mean, the good thing about all this was, I kind of had a living funeral here you know, which is really good, you know, in a way, because I realized I had left my legacy and I’ve changed a lot of people’s lives and for the good, and so I was happy about that, so I thought oh good I’ve done my work so I don’t need to worry about anything there.... And now it’s kind of hard with working again, so that I can have a flat to live in and not be homeless... And so, I had to start working again. And, and of course, with working again, joy goes down, time goes down, rest goes down, spirituality goes down...that’s the problem.

Dwelling on Beatrice’s account, we can observe the positive changes she made to her life as a result of her cancer diagnosis. Beatrice not only survived, but like the hero in the quest narrative she was reborn (Frank, 2013). She was able to live a different life, without possessions and without a home of her own. But as Beatrice survived, she then had to re-engage with a conventional life and the limitations that came with that.

The case of Beatrice provides an insightful view on disruption. Beatrice was able to embrace the extraordinary opportunity provided by the cancer diagnosis to stop work and seek out a different way of being—finding her joy. But as the ‘event’ and disruption turned into a ‘chronic’ ongoing situation Beatrice had to re-establish everyday norms of work and housing, meaning for her that the extraordinary was now returning to the mundane and ordinary. The demands of society were reasserted. For Beatrice there is a perverse disruption in not dying as predicted.

DISCUSSION

This research shows that a number of participants see some benefit coming from their cancer journey, even though a diagnosis of cancer can be frightening, and for many the treatments to fight cancer can be extremely difficult to handle. As such this article has focused on one aspect of participants' narratives, which is in turn selected from what the participants chose to tell. We suggest that cancer, in some scenarios, can provide a license for those so diagnosed to challenge and subvert normative expectations around social roles—and not just institutionalised ones such as those performed through work, but everyday roles and expectations may equally be challenged. For instance, the spectre of a limited time on this earth can change one's relationships to others, and foreclosing longer temporal horizons can open up possibilities, in a temporal paradox that certainty (of death) allows forms of life otherwise plucked away by neoliberal demands for productivity. What might be normatively viewed as deviant, such as being unemployed, may be embraced. As such, a diagnosis of cancer may give license to break out of usual social roles.

A cancer diagnosis can provide a license to breach norms, a license to change one's perspective, and a license to practice life differently. License is given to change relationships, whether to intensify them or sever them, to express affection where affection was not expressed before or to avoid contact with those who were once seen as friends. License is given to be different from what you were, which may be to reject social conventions, such as quitting a job, or to align strongly with certain social conventions, such as becoming more focused and determined in your career or your faith.

Spirituality, including faith, is increasingly understood broadly, and highlighted as a critical aspect of the cancer experience (Egan et al., 2018; Park et al., 2015). A number of participants explicitly discussed their spiritual wellbeing, the changes that their diagnosis induced and increased focus on 'what matters most', a synonym for spiritual priorities. Many Māori hold *wairua* (spirituality) to be at the core of their *hauora* (health/wellbeing): with Indigenous scholars highlighting this centrality (Durie, 1985; Valentine et al., 2017). A spiritual licence is then a possibility in the cancer experience, with opportunities and permission to reconnect with self, others, creativity, nature and/or the transcendent (Egan et al., 2017).

For some of our participants, rather than a passively dependant response to breaking social norms, as Bury found with his participants, and rather than "normalise in the face of disruption" (Bury, 1982), we suggest that disruption provided an opportunity to break from expected norms, and to even pursue the extraordinary. Bury noted that rules of reciprocity could be disrupted with people being 'dependant' on others, but participants in our cancer research could embrace such disruption, such as welcoming the support of others with gratitude and without feeling a need to reciprocate. A cancer diagnosis could then indeed provide a defence against the demands of society (Herzlich, 1973). Whereas Bury suggests that those with chronic illness mobilised resources in efforts to stabilise, we can consider Jay's (2013) use of the term event to suggest that normality may be ruptured and with that rupture a license to escape normative expectations may be established.

One finding from Harold Garfinkel's breaching demonstrations of the 1960s was that those who undertook efforts to elicit the norms of social order through breaching those taken for granted norms would often feel anxiety as a result of participating in such experiments or demonstrations (Gregory Jr, 1982). A cancer diagnosis can provoke anxiety related to a variety of issues—pain from the disease, reactions to treatment and so on—but also anxiety about not being able to perform expected roles such as caring for children. However, this tear in the fabric of life may provoke responses whereby anxiety about performing social roles is of lesser concern, and

the possibility of not performing them is welcomed. Our findings suggest that a cancer diagnosis can provide a license to breach norms as the terms of what one is accountable for have changed. Only those with a life limiting or terminal diagnosis can know what it is like, and there is then capacity to change the rules of their social order.

Drawing on sociologically grounded insights such as biographical disruption and the event, we consider the possibility that for many diagnosed with cancer it can be a license to change. We are not arguing that this is an imperative, or that we should be exhorting those so diagnosed to be positive or even 'see' the positives in their journey. Rather, this interpretation suggests that, in practical terms, life can be lived differently, and we can witness many ways in which people do that. However, as we see with Beatrice, access to financial resources can play an important part in enabling people to live life differently. Some have more opportunities than others. The opportunities for 'license' may vary across class, gender and other socio-demographics, ensuring that the capacity to unravel neoliberal demands is varied, though in what ways this varies requires further study. Within the PTG literature there are different views on whether PTG is a real positive change to identity or an adaptive illusion that is a coping strategy (Sumalla et al., 2009). Our analysis of the accounts we have been given suggests that those with a cancer diagnosis make practical, everyday changes that are permitted by a capacity to breach social norms.

This research study is based on 106 interviews undertaken across Aotearoa New Zealand with over one-quarter of our participants Māori, so providing a rich set of data and a rare opportunity to allow for an in-depth understanding of the experiences of indigenous peoples. However, as with all qualitative research there are many gaps in our coverage that includes ethnicities (few Asian or Pasifika participants), limits on the types of cancer covered, and we did not gather information on sexuality. As such there are many future research opportunities that can be identified in this research study to respond to these and other limitations.

CONCLUSION

Cancer diagnosis as delivering opportunity through license to breach social norms provides an alternative to the concept of posttraumatic growth. Rather than a developmental notion of growth, we suggest a terminology of opportunity and change is more apt. As Broom and Kenny (2021: 84) argue "Amidst the dis/continuity of cancer, affective and temporal relations demand reworking as ideas around the self, others, here, there, then and now are reconsidered". We argue that license is not only given to breach social norms, but also to develop a new version of self (or family) that differs from the pre-cancer diagnosis version. This may mean becoming more affectionate and less judgemental, more culturally adventurous or being more selective about who to relate to or maintain as social contacts. In suggesting that a life-changing diagnosis provides the necessary license and permission to breach social norms, for people to change in response to this unwanted diagnosis, we contribute to and extend the scope of biographical disruption and discontinuity. Our research study also supports a re-framing of cancer narratives, to consider ways of tempering the negative impacts of a cancer diagnosis, and yet remaining cognisant of the struggle that can follow such a diagnosis and the variability in people's capacity to engage with that struggle.

AUTHOR CONTRIBUTIONS

Kevin Dew: Conceptualization (lead); Investigation (equal); Methodology (equal); Writing – original draft (lead); Writing – review & editing (equal). **Kerry Chamberlain:** Conceptualization (equal); Investigation (supporting); Methodology (equal); Writing – original draft (supporting);

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CONFLICTS OF INTEREST STATEMENT

No conflicts of interest.

DATA AVAILABILITY STATEMENT

Data is not publicly available.

ETHICS STATEMENT

Ethical approval for this research was obtained from the Central Health and Disability Ethics Committee (ref 20/CEN/46).

PATIENT CONSENT STATEMENT


All participants consented to participating in the research.

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