

Constructivist Psychology in the care of childhood cancer

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Childhood cancer overview

- ▶ Survival rates for sufferers of childhood cancers have improved markedly over the last 30 years
- ▶ However treatment side-effects are common and many experience continuing physical and psychological sequelae of their illness
- ▶ In the UK long-term multidisciplinary follow-up clinics have been established to monitor patients' progress and offer support where needed
- ▶ Economics require that this service be better targeted at those in most need of help

Psychological characteristics

- ▶ Most childhood cancer survivors are in surprisingly good shape with levels of psychopathology no higher than those reported in the general population
- ▶ However a significant minority suffer from chronic psychological problems often related to illness-related anxieties
- ▶ If it were possible to identify the risk factors associated with these fears, then specialist help could be organised

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The ante-post favourites

- ▶ There are a range of cancers that can affect young people
- ▶ They vary substantially in threat
- ▶ Treatments include chemotherapy (with drugs that have variable side-effects) and surgical interventions (eg amputation)
- ▶ Both illness and treatment variables are related to survival rates and quality of life
- ▶ Surely they will predict anxiety levels too

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Karen's Trusler's thesis

- ▶ Large sample of attenders of long-term follow-up clinic in Leeds, UK (153 in total)
- ▶ Detailed demographic and medical history
- ▶ All completed a brief questionnaire that consisted of the BSI-18 (Derogatis 2000) and a novel self-report measure Karen devised to tap cancer-related worries and intrusive thoughts using items from other measures such as Impact of Events Scale

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Results

- ▶ BSI-18 scores on anxiety subscale were similar to general population with 11% in the clinical range and 89% outside
- ▶ Interestingly depression scores were higher than general population (20% in clinical range as opposed to 9-14%)
- ▶ Global scores matched population norms
- ▶ No gender differences (unexpected)
- ▶ Just under half of the group worried at least "a little bit" about cancer returning

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Results continued

- ▶ Regression analysis undertaken to see if any of the data collected from medical files could predict membership of the high anxiety group and/or the reported level of intrusive thoughts (IoE scale items)
- ▶ Correlation table used to determine "best bets" to enter into regression analysis
- ▶ Demographic factors (eg age; gender) entered initially followed by illness factors (eg cancer diagnosis; type of treatment)

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Conclusions

- ▶ None of the illness or demographic variables on which data was available were able to predict membership of high anxiety group
- ▶ Having had a particular form of cancer (sarcoma) did predict intrusive thoughts to a small degree
- ▶ Overall Karen concluded that "the combined illness and demographic variables for both regressions were only marginally better at predicting anxiety or intrusive thoughts than could be predicted by chance"

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How come?

- ▶ George Kelly argued that if you want to understand how somebody is feeling, why not ask them they might just tell you...
- ▶ So Karen did just that with a sub-sample of her participants using a number of questioning techniques derived from personal construct theory (of more later)
- ▶ She got some very interesting responses

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D's Kellian explanations

- ▶ "Being ill is quite comforting in a way, because you're kind of in the middle of it, you know when your next hospital appointments are and things like that ...it sounds really bad but you don't want to leave it behind a little bit because it's what you knew for so long, it becomes part of your life and shutting the door on it, I feel like it would be a bit bad luck if I did not think about it sometimes, I feel like I need to spend a bit of energy on it".

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Post-traumatic growth

- ▶ "You would not want to go through it but there are good things that came out of it".
- ▶ We generally believe that certain "bad" life events will inevitably lead to negative psychological consequences (such as bereavement and life-threatening illness)
- ▶ However there is *huge heterogeneity* in outcome after a wide range of adversities in childhood
- ▶ What's going on?

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Research with adolescent cancer survivors

- ▶ US study by Barakat et al (2006)
 - 150 cancer survivors aged 11-19 and their parents and siblings
 - Off treatment at least 1 year
 - Range of diagnoses - leukemias (30%); solid tumours (35%); lymphomas (21%)
 - Mean age at diagnosis = 7.9 years (range from 3 months to 16.4 years)
 - Decent balance of gender and ethnicity

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Measures employed

- ▶ Perception of Changes in Self - 45 item semi-structured interview
- ▶ Intensity of Treatment ratings - completed by paediatric oncologist and nurse practitioner
- ▶ Assessment of Life Threat and Treatment - self-report likert scales
- ▶ Impact of Events Scale (Revised) - 22 item measure of post-traumatic symptoms

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Results (teenage patients)

- ▶ 84.1 % of adolescent survivors reported at least one positive benefit of having had cancer and 32 % identified 4 or more
- ▶ Most common benefit was a positive change in "how they think about life"
- ▶ PTG correlated positively with the survivors' perceptions of greater life threat and greater treatment intensity
- ▶ PTG and post-traumatic symptoms also positively correlated (unexpected finding)

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Mechanism?

- ▶ Not clear as positive psychology has been a bit slow off the blocks
- ▶ Genetics likely to be implicated (cf link between child abuse and depression)
- ▶ Social support from family and friends
- ▶ Personality factors under examination (eg resting hedonistic level theory and differential susceptibility hypothesis - Pluess and Belsky 2009)
- ▶ Cognitive re-appraisal and rewriting your life narrative seems promising line of research (Tedeschi and Calhoun 2004)

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A Kellian postscript (Butt 2004)

- ▶ Orthodox accounts of trauma see them as "impacting" on people, causing more or less damage, depending on the material they hit. But an understanding of a traumatic event involves seeing it from the traumatised person's point of view. It is the interpretation of the event that matters, rather than the event itself. The lived world is ambiguous and open to many interpretations, not just those that jump out at us, as external observers

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Case Study One

A Touch of Cancer

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The physical bit

- ▶ R was diagnosed in 1995 as having Synovial Sarcoma in his neck
- ▶ Lesion surgically removed - "a complete excision with clear margins" and some reconstructive surgery
- ▶ No problems at follow-up. "Extremely healthy" (June 1998) "Extremely well" (August 1999)

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Psychological concerns

- ▶ At age 15 R is struggling somewhat
 - Sensitive to cancer-related material on the TV
 - Parents describe "mood swings" particularly angry outbursts. At school linked to being teased - "cancer boy"
 - Critical of religious faith
 - Some suggestion of bullying himself

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Why now?

- ▶ No evident external stressors in school or family
- ▶ No cancer related complications
- ▶ Perhaps greater physical self-consciousness over scarring
- ▶ "Something here about thinking more deeply about having had cancer in the past"

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Elaboration of complaint

- ▶ **After effects.** Scars cannot be hidden. Always noticed. Have to be explained somehow
- ▶ **How other people treat you.** Some boys called R "a liar" when he explained his scarring. He found girls more sympathetic and reliable

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Self-respect

- ▶ What do you reckon of yourself R?
 - How I am now - 4/10
 - How I'd like to be - 8/10
 - How I think I would have been if I hadn't had cancer - 8/10
 - As if cancer had spoiled him for ever more like the effect of an early frost on a spring shoot

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Not just a sad story

- ▶ R's sense of hopelessness and injustice came across strongly
- ▶ But he also acknowledged the good things in his life particularly his family and how much they mattered
- ▶ R spoke with a level of candour and consideration that surprised his parents and impressed the hell out of me

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The letter

- ▶ The story that I heard about you (and from you) at that time went along the lines that you were a bit of a terror; had a bad temper you couldn't control; couldn't put your feelings easily into words; and even felt that your chances in life had been ruined by having cancer as a young child

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Continued...

- ▶ I don't think of you that way at all now. If I were telling your tale I'd notice quite different qualities in you. I'd start by talking about your emotional maturity. I've been really taken by the way you've been able to talk about what you're going through. It's helped me and your parents understand more and I suspect it's helped you make better sense of things too.

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Continued...

- ▶ You've also showed in your comments in our sessions an unusual wisdom and ability to reflect (I know you like that word). I've sometimes noticed this strength in other young people who have had cancer as children. It's as if the experience can help you realize what matters in life a bit more quickly than others of your age

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Some family therapy principles

- ▶ Look out for exceptions to the problem-saturated account
- ▶ Listen out for the subjugated tale of solutions and competence
- ▶ Weave together a story from instances of atypical actions to construct a new narrative
- ▶ Support this new identity by publicly acknowledging achievements

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Case study Two Rosie - the Real Experimenter

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A little history

- ▶ Rosie was discovered to have a brain tumour at age 13
- ▶ Her treatment included both intensive radiotherapy and powerful chemotherapy
- ▶ Her appetite was compromised by these treatments and she was fed through a nasogastric tube for a long period of time
- ▶ She survived but at the price of serious visual impairment

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The referral letter

- ▶ In many ways Rosie emerged from these experiences surprisingly unscathed
- ▶ The referring oncologist mentioned only her concern that Rosie seemed oddly attached to her feeding tube which she called her "friend"
- ▶ Medical and nursing staff could not understand why she opted to continue with the nasogastric feeding when she was now perfectly capable of eating normally

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The credulous approach

- ▶ Interesting word for Kelly to use
- ▶ Not usually a compliment - means unsuspecting at best and gullible at worst
- ▶ "The client, like the proverbial customer, is always right" - beyond collaboration!
- ▶ Not the usual way for health professionals to communicate with their patients
- ▶ Or for adults to talk to young people...

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A central PCP principle

- ▶ No matter how self-defeating or irrational a person's behaviour may seem when seen from the outside it will make perfect sense if seen from the actor's perspective
- ▶ It may seem obvious that Rosie should resume normal eating patterns but it is the therapist's job to "transcend the obvious"
- ▶ Let's assume that Rosie is making an informed and psychologically sound choice

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The Choice Corollary

- ▶ "A person chooses for him, or her, self that alternative in a dichotomized construct through which he or she anticipates the greater possibility for extension and definition of his or her system"
- ▶ Extension is the adventurous option
- ▶ Definition relates to predictability
- ▶ Kelly never said when which of these competing principles would apply!

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An imaginative leap

- ▶ Actor-observer differences in psychology
- ▶ Visual metaphors (eg lenses) abound in PCP
- ▶ What would we notice if we saw the world through Rosie's eyes - not much!
- ▶ The tube that grates on the observer's eye rarely comes into her view. Her vision is blurred and she doesn't much like mirrors
- ▶ Her friend the tube was with her through her darkest hours - a transitional object

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The power of anticipation

- ▶ If you have no adequate way of anticipating the future the elaborative choice feels like walking the plank
- ▶ Fransella in the 1970s worked with stammerers who struggled to change even when they were technically fluent speakers
- ▶ They needed to learn to anticipate their social world from the perspective of a someone who did not expect to stammer

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So...

- ▶ We agreed that Rosie was perfectly capable of deciding for herself when she wanted to experiment with other ways of getting her energy supplies
- ▶ She was the expert on her own condition
- ▶ We talked about foods she used to enjoy (like popcorn at the cinema) and how her life might change if she ate differently
- ▶ But no negotiated goals or homework tasks

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Encouraging signs

- ▶ Sessional alliance measures showed Rosie liked this approach as did her parents
- ▶ Plenty of playful banter with both parents including the introduction of imaginary flavours to the formula feed ("I think it will be fish and chips tonight, Mum")
- ▶ And so in her own time and in her own way Rosie started to resume normal eating and eventually bade her friend farewell

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Competing priorities

- ▶ The approach that worked well with the tube also helped Rosie with her fear of needles and injections
- ▶ However our conversations got stickier when discussing how Rosie might grow increasingly independent of her parents despite her physical limitations
- ▶ I did not find it hard to tune into a fellow parent's painful dilemma...

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The resistance-to-change grid

- ▶ Hinkle devised several ways of discovering which constructs were most important and influential in a person's scheme of things
- ▶ The resistance-to-change grid elicits a person's self-constructs; identifies their preferred pole; and gets them to rate themselves on each of the constructs
- ▶ Every pair of constructs is then examined in a painfully personal manner

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Hinkle's challenge

- ▶ If you have to move towards your less-preferred pole on one of two constructs, on which do you opt to stay the same?
- ▶ As the parent you are, or on behalf of the parents you had, try this one for size
- ▶ The two provided constructs are:
 - Promote my child's independence
 - Protect my child from harm

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There may be troubles ahead but...

- ▶ Rosie completed session-by-session outcome and alliance measures for me (Miller and Duncan's ORS and SRS)
- ▶ Her consistently positive ORS scores were supported by her parents' proud recognition of her psychological resilience
- ▶ Indeed her Dad reckoned she had "bounced back" stronger than ever

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Developmental themes

- ▶ Adolescence generally exerts a centrifugal force on family dynamics
- ▶ Life-threatening illness exerts a compelling centripetal force on relationships
- ▶ Families cling together to look after each other in crisis (Rolland 1987)
- ▶ Poignant tableau of parents and siblings huddled round the hospital bed of their sick child

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Protection and autonomy

- ▶ Parents concern for their children's safety can lead them to take decisions on their behalf
- ▶ Young et al (2003) reported that, particularly at times of crisis, young cancer patients are "relegated to non-participant status" in family consultations with their oncologist
- ▶ Kelly's advocacy of adopting a "credulous" approach
- ▶ Salmon on the competence of children

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Salmon on childhood

- ▶ "We think of childhood as essentially entailing incompetence. Children's lack of competence forms the constant basic theme of psychological research, which typically focuses on what a child cannot do rather than on what she or he can. More generally we view the young in the perspective of helplessness, ignorance, neediness - as requiring to be guided, taught, brought up."

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Emerging Adulthood

- ▶ A recognition that in USA and Western Europe the transition to adulthood is taking longer nowadays and the markers of having become grown-up are much less certain (Settersten et al 2005)
- ▶ See extended period of education; delays in marriage and parenthood; economic and job uncertainty; less and later leaving home
- ▶ Can be problematic for particularly vulnerable sub-groups such as those leaving care and those suffering from chronic illness

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Opportunity or threat?

- ▶ Since young cancer survivors run the risk of having their education disrupted; possibly limited employment prospects; may have impaired fertility and are less likely to marry, is the idea of "emerging adulthood" a help?
- ▶ Yes if you can find other legitimate ways of defining yourself as an adult - being creative; developing opinions; peer attachments
- ▶ No if you feel left behind and, for some, conscious of looking younger than your age

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Too close for comfort?

- ▶ Kelly's sociality corollary states that " to the extent that one person construes the construction processes of another they may play a role in a social process involving the other person"
- ▶ Often adolescents and their parents get to know and appreciate each other greatly through coping with cancer
- ▶ Impressive sensitivity to each others' feelings

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A special relationship...

- ▶ Generally we want parents and their teenage offspring to understand each other better - see runaways and systemic family therapy
- ▶ But could it also be important for adolescents to retain some areas of personal privacy about which their parents are ignorant?
- ▶ Is there a danger that others who understand the cancer sufferer in different ways from their parents (eg boy/girlfriend) will get pushed out of their support system?

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Masche (2010)

- ▶ Large scale longitudinal Swedish study in which >2400 adolescents aged 13-18 completed annual questionnaires on how much they let their parents know about their lives
- ▶ As predicted teenagers progressively kept more of a "private space" for their experiences over time. Slightly more so for boys than girls
- ▶ Less disclosure to parents; more secrecy; and use of peer supports and boyfriend/girlfriend

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But parents can adapt...

- ▶ By becoming less controlling and hence heading off defiant reactions from their offspring
- ▶ Sensitively soliciting information from their adolescents rather than leaving them with the responsibility for sharing information
- ▶ Maybe also in the spirit of the sociality corollary understanding why, from their son or daughter's point of view it has become important to establish a life that is separate and even secret from their parents

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Getting to know you...

- ▶ The wise words of Tom Ravenette
- ▶ Children know more than they can easily say
- ▶ The contents of children's consciousness do not stand to attention for us to examine them
- ▶ So how might we engage young people in conversations that allow us (and them) to discover more about their constructions?
- ▶ A few ideas from Personal Construct Psychology...

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Repertory Grids

- ▶ Various ways of inviting children to describe some aspects of their lives (Elements) using adjectives that make sense to them (Constructs)
- ▶ Dependency (or Situational Resources) Grid
- ▶ Resistance-to-Change Grid
- ▶ The Self-Image Profile (SIP)

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Dependency Grids

- ▶ Map the problems with which a person must deal against the supports available to them
- ▶ Example of 20 year old girlfriend of a young man who had a recurrence of a brain tumour
- ▶ They had come to rely exclusively on each other (as lovers sometimes do) but she felt she could no longer turn to him as before
- ▶ To whom could she turn for what help?
- ▶ Discovered how useful her younger brothers were when she just needed to "chill"

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Resistance-to-Change Grids

- ▶ A way of investigating what changes are most important in the individual's view of things
- ▶ Understanding why a 13 year-old boy with a chronic urinary problem regularly risked getting infections that seriously threatened his health by not keeping warm in the winter
- ▶ NB This young man did not enjoy seeing a psychologist at all and would answer most of my carefully phrased questions with "Dunno"

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Self-Description

- ▶ Just like everyone else v not the same as others (1)
- ▶ Has fun v maungy (5)
- ▶ Sensible v silly (4)
- ▶ Have to work for everything v get things given to you on a plate (6=)
- ▶ Childish v Grown up (3)
- ▶ Handicapped by ill-health v feeling well (2)
- ▶ Does things for himself v a born delegator (6=)

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THE SIP

- ▶ Developed by Butler and confederates in UK to try and help children and adolescents give a sense of their view of themselves
- ▶ Ravenette's "3 things about you" question
- ▶ Responses from >2k children and adolescents in general population in Yorkshire UK
- ▶ Qualitative and quantitative analysis resulting in 25 item questionnaire (12 +ve & 12 -ve)
- ▶ How you see yourself now and how you'd like to see yourself (self-image and self-esteem)

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A few other ideas

- ▶ Using drawings and stories
 - The WAY approach
 - Someone's Suffering
- ▶ Elaboration of complaint
- ▶ The self-characterization
- ▶ Sentence Completion exercises
 - Personalised questionnaires
 - Standard format (allows normative scoring)