

01 **The Literature Notes and Codes:**

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03 **PAPER 1:**

04 Faircloth, Christopher A., Boylstein, Craig, Rittman, Maude, Young, Mary Ellen & Gubrium, Jaber (2004) 'Sudden illness and biographical flow in narratives of stroke recovery', *Sociology of Health & Illness*, 26(2); pp.242-261.

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06 (p.244) Not all physiological changes resulting from a particular chronic condition have the same impact on people's lives. The lives of people who have a stroke are not inevitably disrupted. ... While some find their lives disrupted by the stroke, others may 'bracket off' the impact of the stroke, maintaining a sense of a coherent pre- and post-stroke self.

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08 (p.252) ...rather than the stroke being a source of biographical disruption it is simply expressed as one event in an ongoing life.

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10 (p.256) We have suggested that instead of disrupting a biography, an illness such as stroke can be integrated with various social contingencies in constructing a biography that continues to flow across time and space. ... The ill 'are theoreticians of both illness and the body and are not simply passive in the face of illness and medicine', but are actively working towards maintaining a certain level of quality of life.

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12 (pp.258-9) Treating all survivor experiences as universal may gloss over some important aspects of the survival experience.

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15 **PAPER 2:**

16 Asbring, Pia (2001) 'Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia', *Journal of Advanced Nursing*, 34(3).

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18 A transformation of identity was described in various ways in the interviews. ... The consequences of a biographical disruption for identity does not ... have to be unequivocal: it can be expressed either as a partial transformation of identity - i.e. a somewhat changed identity, or as

FEATURES: not a universal experience

STRATEGIES: not just passive

FEATURES: not a universal experience

FEATURES: different experiences?
TENSIONS: questions 'heathness' of transformation

- 19 two completely discrepant identities.
- 20 The disruption may vary in significance and bring with it various consequences for different people. Some may, depending on the symptom profile, maintain more of the activities important to their identity than others. The interview responses showed, therefore, that biographical disruptions were partial rather than total. (Some, for example, managed to keep working.)
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- 22 Biographical disruptions were not viewed as entirely negative by the interviewees. The illness experience may also have brought with it positive changes in identity, because of new insights with regard to the previous life and life in general. Paradoxically the dilemmas to be faced, for some, also became positive experience.
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- 25 **PAPER 3:**
- 26 Mathieson, Cynthia M. & Stam, Henderikus, J. (1995) 'Renegotiating identity: cancer narratives', *Sociology of Health & Illness*, 17(3), pp.283-306.
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- 28 (p.288) Self-narratives are part of an open-ended process, with continuous transformations, which provide a meaning to daily interactions. As such, these narratives are social constructions; they emerge from social interchange. No single narrative is ever final but part of the negotiation of ongoing, intersecting and multiple influence. These constructions of narrative order are essential in providing one's life with meaning and a sense of direction for the future.
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- 30 (p.293-4) ...personal identity (has been described) as a 'feeling of fit' that develops among the individual's past, present, and the meanings available for interpreting such experiences. We used this terminology 'disrupted feelings of fit' to characterise early signals of threats to identity. In the early stages of a cancer diagnosis, participants were beginning to identify the discrepancies between their former health lives and their lives revised by illness. ... Some discrepancies arose from disruptions to daily routines caused by medical intervention Participants (also) alluded to disruptions of relationships with friends ... and the bodily disruption involved (in treatment)
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STRATEGIES: seeing in a positive light

STRATEGIES: negotiated narratives

FEATURES: impact on relationships
FEATURES: threat to identity

32 (p.299) Individuals engage in biographical work over the life span as a stable requirement of identity; events of one's life must be articulated in a coherent story. ... it seems that a diagnosis of cancer challenges older self-narratives and motivates the search for newer narratives that incorporate the meaning of illness. The cancer patient must ultimately decide how the events of illness fit in among the other event of her life. This inevitably entails revisions of future plans..

FEATURES: challenge to existing narratives

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34 (p.300) Here then are the major biography-altering facts of cancer: altered relationships, a curtailed sense of agency, and a changed vision of the future.

STRATEGIES: re-constructing the future

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38 **PAPER 4:**

39 Exley, Catherine & Letherby, Gayle (2001) 'Managing a disrupted lifecourse: issues of identity and emotion work', *Health*, 5(1); pp.112-132.

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41 (p.112) (Both) 'infertility' and/or 'involuntary childlessness' and terminal illness have a disruptive effect on daily lives and future expectations.

FEATURES: threat to future plans

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43 (p.114) Social identity theory suggests that identity rests on the process of social comparison, whereby in order to evaluate their own opinions and abilities individuals compare themselves with similar others in the course of social encounters ... We would suggest that terminally ill people and those who are 'infertile'/'involuntarily childless' may perceive themselves as a 'stranger' in social encounters with others, and further their status as terminally ill or 'infertile'/'involuntarily childless' affects their relationship with others and their sense of self.

FEATURES: comparison with others

FEATURES: impact on relationships

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45 (p.115) In addition, as we will argue, from our respondents' accounts, it is possible to suggest that such disruption can have positive as well as negative effects on self-identity, but achieving such positive effects often involves hard work. 'emotion work' (involves) regulating and managing others' feelings.

STRATEGIES: emotion, work

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47 (p.125) ... respondents are managing strong emotions such as jealousy and grief and struggle with concerns about how to make themselves and/or others feel better.

- 48 (p.124) ... complex processes are at work here, respondents wanted others to recognise the
49 disruption they were experiencing, yet did not want to be excluded from discussions focussing on
50 expected lifecourse progress and events. Thus, whereas they wanted their 'strangerhood' to be
51 acknowledged, they did not want to be treated like 'outsiders'.
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- 54 (p.129) Emotion work, for the respondents in our research, was a means of reaffirming their
55 identities as people who were still part of the mainstream groups, not just individuals who were
56 terminally ill or 'infertile' and/or 'involuntarily childless'. Thus, there is a link between emotion
57 work and lifecourse disruption.
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- PAPER 5:**
- Hallowell, Nina & Lawton, Julia (2002) 'Negotiating present and future selves: managing the risk of
hereditary ovarian cancer by prophylactic surgery', *Health*, 6(4), pp.423-443.
- (p.428) Control - or loss of control - was the major theme that underpinned all of the women' accounts.
On the one hand, women talked about oophorectomy as providing them with a means to regain control
over their bodies, as enabling them to manage their risk of cancer and thereby to ensure the survival of
self in the future. On the other, they described prophylactic surgery as precipitating a loss of bodily
control, as potentially undermining their self-identity in various ways. as far as these women are
concerned, choosing surgery requires them to balance the contradictory effects of oophorectomy on
their present and future selfhood.
- (p.431) The women involved in this study repeatedly talked about the ability to reproduce as
being central to 'being a woman'. Thus, insofar as losing one's ovaries results in a loss of control
over one's fertility, it was described as compromising one's femininity.
- (p.438) as this article has demonstrated, in reality the management of ovarian cancer by
prophylactic surgery requires careful consideration of the costs and benefits for present and future
self-identity.

FEATURES: getting left behind
FEATURES: impact on relationships

STRATEGIES: emotion, work

FEATURES: loss of control & choice
FEATURES: threat to identity

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65 **PAPER 6:**
66 Williams, Simon J. (2000) 'Chronic illness and biographical disruption or biographical disruption
as chronic illness? Reflections on a core concept', *Sociology of Health & Illness*, 22(1); pp.40-67.
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68 (p.41) Does a focus on 'disruption' mask as much as it reveals? Can equal weight be accorded
both to chronic illness' role in the creation of biographical disruption and biographical
disruption's role in the creation of chronic illness? Finally ... are these process confined to
chronic illness?
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70 (paraphrased) Is re-negotiation of identities/biographical disruption a feature only of responses to
chronic illness or is it more pervasive in relation to dealing with 'normal crises' - and therefore
useful for understanding a wider range of experiences and situations?
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72 (p.57) Confronted with a pluralization of life-style options and choices about everything from the
food we eat to the clothes we wear, the occupations we pursue, to the sexual identities we adopt,
the management of our bodies and our emotional selves becomes a continual process of
biographical revisions and reversals, successes and failures.
- TENSIONS: questions direction of influence
- FEATURES: loss of control & choice
STRATEGIES: reconstruction (ongoing)

FIG 11.1 P1: THE LITERATURE NOTES AND CODES. DOC

NB: I have not listed the accompanying papers chronologically, but have, instead, ordered them in a way that aids the developing argument and associated refinement of the various theoretical concepts invoked by the over-arching theme of 'biographical disruption'. You may wish to read the notes (and, indeed the data excerpts) while covering up the accompanying coding framework, allowing you to compare notes later.