

Illness, Crisis & Loss

Co-creation or collusion: The dark side of consumer narrative in qualitative health research

Journal:	<i>Illness, Crisis & Loss</i>
Manuscript ID	ILL-16-0007.R1
Manuscript Type:	Original Articles
Keywords:	Loss < Bereavement, Cancer < Illness, Qualitative data < Research methods, Phenomenology < Theory, narrative, mental health
Abstract:	<p>Health, mental health and social care policy are dominated by the imperative of employing person-centred approaches. Such involvement of the 'consumer' is generally claimed to provide a counter-narrative to the psychiatric and medical paradigm of illness. Taking a critical and reflexive standpoint, we find ourselves asking: Is there a dark side to employing person-centred approaches and potential loss and risk to participants themselves?</p> <p>To explore these questions further we undertook a condensed critique of the current mental health, health and social care policy arena. We then move to methodological concerns about ways in which person-centred research, including our own, can inadvertently reproduce the neoliberalist agenda.</p> <p>To conclude, we offer our own lived experiences as a cautionary tale. We also posit that a post-Foucauldian governmentality framework can assist researchers to avoid contributing to the very problems we wish to resolve.</p>

SCHOLARONE™
Manuscripts

Abstract**Co-creation or collusion: The dark side of consumer narrative in qualitative health research**

Health, mental health and social care policy are dominated by the imperative of employing person-centred approaches. Such involvement of the ‘consumer’ is generally claimed to provide a counter-narrative to the psychiatric and medical paradigm of illness. Taking a critical and reflexive standpoint, we find ourselves asking: Is there a dark side to employing person-centred approaches and potential loss and risk to participants themselves?

To explore these questions further we undertook a condensed critique of the current mental health, health and social care policy arena. We then move to methodological concerns about ways in which person-centred research, including our own, can inadvertently reproduce the neoliberalist agenda.

To conclude, we offer our own lived experiences as a cautionary tale. We also posit that a post-Foucauldian governmentality framework can assist researchers to avoid contributing to the very problems we wish to resolve.

Co-creation or collusion: The dark side of consumer narrative in qualitative health research

Introduction

Health, mental health and social care policy are dominated by the imperative of employing person-centred approaches. Policy has been reconfigured to specify the value of the voices and lived experiences of service users and patients, as well as that of working with them in collaborative partnership (King's Fund, 2016; Nesta, 2016; NHS England, 2016). Such involvement of the 'consumer' is generally claimed to provide a counter-narrative to the psychiatric and medical paradigm of illness, instead offering one which *'belongs to consumers-survivors, not to practitioners'* (Schiff, 2004:212). As health researchers, we consider such policy reform preferable to expertism; nonetheless we do question if such well-intentioned, person-centred approaches are inherently 'good'. Taking a critical and reflexive standpoint, we find ourselves asking: Is there a dark side to the inclusion and use of person-centred approaches and what might be at risk in this pursuit of 'voice'?

To explore these questions further we offer a condensed, but critical, exploration of the current mental health and health and social care policy arenas, with a focus on how neoliberal policy generates particular discourses, which in turn shape research and practice. From this policy perspective, we then move to methodological and ethical concerns about ways in which collaborative and person-centred research can inadvertently reproduce the neoliberal agenda. We do this with a view to adding to current debates, particularly in qualitative interviewing, around power relations and positionality.

1
2
3
4
5 Informed by a Post-Foucauldian governmentality analysis (Marston & McDonald, 2006) we
6
7 set about reimagining our current research into mental health narratives (author a) and
8
9 psychosocial cancer care (author b). Our reanalysis aims to explore the subtle workings of
10
11 power and its imbrication with forms of knowledge. We pay attention to how particular sorts
12
13 of participants are produced (in this case the mental health service user; the cancer patient)
14
15 and how our research is complicit in this reproduction. We have become increasingly alarmed
16
17 that even critically reflexive research runs the risk of perpetuating dominant discourses in
18
19 health, as evidenced by the recovery and remission narratives, thereby contributing to the
20
21 very problems we wish to resolve. We seek to explore these concerns here, and offer our own
22
23 lived experiences as a cautionary tale.
24
25
26
27
28

29 **The Policy Context**

30
31 Consumerism as an ideology within UK health policy has been linked to the rise of
32
33 managerialism in the National Health Service (NHS) during the 1980s. The drive toward
34
35 'patient-client' participation foregrounded the 'consumer voice' movement and private sector
36
37 edicts of market forces, assessment and audit have underpinned the continued rise of
38
39 managerialism (Loewenthal, 2002), and neo-bureaucracy (Harrison & Smith 2003),
40
41 privileging technicism and performativity over basic trust in public sector professionals
42
43 (O'Neill, 2002).
44
45
46
47
48

49
50 The *NHS and Community Care Act of 1990* is widely cited as the first UK legislation to
51
52 establish a formal requirement for user involvement in service planning although historians of
53
54 public health have described a heritage for public participation dating back 200 years
55
56 (Gorsky, 2007). The act enshrined key objectives of the government White Paper *Caring for*
57
58
59
60

1
2
3 *People* (1990), which promoted the concept of the state as enabler, rather than provider, of
4 care through the application of privatisation. Subsequent policies in the early 1990s include
5 the Patient's Charter (Department of Health, 1991) and plans set out in *Local Voices* (NHS
6 Management Executive, 1992) which aimed to make services more responsive to patients'
7 needs, stressing, however, consumerism rather than partnership. Patient and public
8 involvement in healthcare was to become one of the central tenets of New Labour's
9 modernisation agenda. Its energetic acceleration by the subsequent Coalition Government
10 paved the way for the current swingeing radical reforms and cuts to services under the
11 Conservative government. This drive toward a particular version of healthcare was not
12 confined to the UK; as a consequence of policy reform, user /patient/client voice are now part
13 of policy and an expectation of practice across post-developed countries. So embedded an
14 approach is it that the problems of participatory mechanisms of governance are well
15 documented, including tokenism (obligatory consultation with minimal dispersed decision
16 making power) and a co-option or incorporation of critics (Pilgrim, 2005). Cooke and Kothari
17 (2002) suggest that policies seeking to promote public engagement are merely one part of a
18 deeper mission of governance and social control.

19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41 In this version of healthcare the individual is forefronted, unsurprisingly, as s/he is identified
42 as a key cultural trope (Wacquant, 2012) of neoliberal ideology – with the consequent erosion
43 of any sense of community or obligation to others (Bauman, 2007). The 'active' involvement
44 of this individual in health care policy is very much part of the neoliberal package, with its
45 crafted versions of community and volunteerism engineered to enable a shrinking welfare-
46 state presence (Brown & Baker, 2013).
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Policy shapes the research context

Much health research has, unintentionally, colluded in this shift toward individualism, albeit under the guise of participation, collaboration and co-production. An emphasis on ‘voice’ in particular, apprehending the discourse of activism ignited by the civil rights and user/survivor movements and struggles of the 1970s, is apparent throughout contemporary policy and practice guidelines. Such hijacking of language has been better conceptualised as **examples of discursive elements becoming incorporated into chains removed from their original. Hall (2011) amongst others, has given account of how neoliberalism appropriates extensively from classic liberal ideas, giving them a ‘market’ inflection and conceptual revamp.**

Health research, much of it emanating also from the emancipatory agenda of the 1970s (Freire, 1970; Hubert, 2002) has developed a strong qualitative, first person narrative pedigree – and quite rightly. Part of a broader shift across disciplines to narrative knowing, such work has illustrated precisely how the personal is political, and exposed the micro of experience within complex social matrices (Andrews et al, 2013).

The early health consumer movement was emancipatory in that it sought to challenge medical power, yet today the ways in which these voices are disseminated and find their way into policy and practice may not always be as equitable as is commonly assumed. In terms of policy, research that often painstakingly foregrounds the participant voice may well be contributing to the individualistic veneer of neoliberal policy being ‘person centred’ /collaborative/ participatory/democratic, while inadvertently leading to the loss of complexity of illness experience. A further outcome of this may be the sequestering of voice into a position where it can pose no threat; a ‘naturalising’ of the language of resistance, rendering the ideology opaque (Fairclough, 2010). This hijacking of language leaves actual ‘resistance’

1
2
3 discourse denuded, its voice neutered; a further loss of power of the ‘other’. As Rose (1999)
4
5 argued, the capacity of the individual for action is thus used as a means to secure the aims of
6
7 government.
8
9

10
11 We continue to endorse the need for research to include the voices and experiences of
12
13 participants and we do not suggest that narrative research inevitably leads to a reinforcing of
14
15 languages of deficit; blame or victimhood. Neither do personal testimonials or blogs detailing
16
17 illness necessarily fall prey to this. Barbara Ehrenreich’s famed ‘Welcome to Cancerland’
18
19 being a much heralded example of a first person rumination on the cancer journey which, far
20
21 from succumbing to any discourse of blame, victimhood or deficit, defiantly makes a critical
22
23 point about the ‘cult of pink kitsch’ and the ‘breast cancer paraphernalia’ with which our
24
25 culture is saturated.
26
27
28
29

30
31 We also acknowledge that practice, policy and theory are all strengthened by research, each
32
33 informing the other to ultimately shape the ways in which we reproduce discourses and
34
35 facilitate understanding ourselves as meaning-making subjects. Indeed, as researchers aligned
36
37 to feminist onto-epistemological principles (Brown, Western and Author b, 2013), our own
38
39 narrative work continues to point to the value of reflexive, first person interviews (Author a,
40
41 2014) that function both to foreground voices otherwise marginalised and to provide what is
42
43 seen by some as a resource on which people can draw as part of their re-scripting and
44
45 narrative rebalancing. Yet we find ourselves caught in a ‘wicked problem’; caught in the
46
47 perennial tensions between public discourse and personal experience, asking what knowledge
48
49 and experience is privileged (Finlay and Gough, 2003) and what complexities are lost in this
50
51 as we explore privately based knowledges and personal understandings and then reconstitute
52
53 them within publicly based disciplinary knowledge. Although we cannot hope to resolve
54
55
56
57
58
59
60

1
2
3 'wicked problems' in our paper, nonetheless, we regard this dilemma, first highlighted by
4
5 Ribbens and Edwards in 1998 as more pressing than ever, as neoliberal ideals penetrate more
6
7 deeply into the research agenda and as academic research becomes more entrenched in, part
8
9 of, and beholden to their discourse.
10

11 12 13 14 **Methodology:**

15
16 We have employed a post-Foucauldian governmentality analysis to our recent research into
17
18 mental health narratives and psychosocial cancer care (Author b, Johnson, Dickson-Swift
19
20 and Kenny, 2015; Author b, Johnson, Dickson-Swift, McGrath & Dangerfield, 2015; Author
21
22 b, 2010; Author b and Endacott, 2010; Author a, 2012, 2014:,2015; more specifically, a
23
24 'realist governmentality' approach (Stenson 2005, 2008) which attends to the 'messy
25
26 actualities of the empirical world' (McKee, 2009:484). Foucault defined governmentality as
27
28 the 'institutions, procedures, analyses and reflections, the calculations and tactics' that
29
30 support a particular rationale of power and apparatuses of security, with populations as their
31
32 target (Foucault 1978: in Burchell et al. 1991: 102). In this paper, we also offer a condensed
33
34 view of the procedures of particular methodologies (first person narrative and
35
36 phenomenology) with participants drawn from mental health service user groups and cancer
37
38 psychosocial care respectively. Thus, a triangulation of post-Foucauldian governmentality
39
40 analysis, combined with narrative and phenomenological interpretation, offered a rich, if
41
42 complex, methodological approach.
43
44
45
46
47
48

49
50 As our work encompasses multidisciplinary and multi methodological approaches, we
51
52 nevertheless found our work situated within person-centred and socially-just epistemologies.
53
54 Applying a critically analytic 'meta-analysis' to our own work offered a platform from which
55
56 to examine our own potential collusion with neoliberal agendas, and ways we sought to
57
58
59
60

1
2
3 overcome this. This process allowed space for us to consider ‘the effects of power at the
4
5 micro-level and the lived experience of subjection’ (McKee, 2009).
6
7

8
9
10 We concede given Higher Education policy imperatives that researchers cannot eradicate
11
12 embedded assumptions. However, working within that caveat we offer that reflexivity and
13
14 rigour can ameliorate dilemmas and facilitate a move toward a more socially-just and
15
16 inclusive standpoint.
17

18
19
20
21 (i) Reflexivity
22

23
24 To be reflexive is to be able to name and critique one’s own values and how these influence
25
26 the design of research projects and the interpretation of findings (Chamberlain, 2015). But
27
28 such self-awareness is not sufficient to ensure criticality; indeed within the psychosocial
29
30 narrative research tradition that admits to unconscious processes in research (Hollway &
31
32 Jefferson, 2000) the field (which for reasons of brevity is not discussed in this paper)
33
34 becomes further ignited. But we do, at this juncture posit that an ongoing and iterative
35
36 process of reflexivity is required to remain ethical. It was in taking such a standpoint that we
37
38 found ourselves troubled by research participants’ stories that spoke to self-shame and blame;
39
40 to not coping. We were struck too by the pervasiveness of converse narratives; segments that
41
42 repeated acts of ‘soldiering on; keeping smiling; and oh well...staying positive’; as well as
43
44 narratives of ‘reason’: ‘I got cancer/schizophrenia for a reason/lesson/punishment’. These
45
46 recurring (and indeed polarised) themes seemed to pick up the individualistic and ‘victim-
47
48 blaming’ neoliberal discourse, through which participants unwittingly isolated themselves
49
50 from the socio-political contexts of their lives. We became increasingly concerned that our
51
52 research inadvertently reproduced and sedimented disempowered identities reinforcing
53
54
55
56
57
58
59
60

1
2
3 marginalisation and deficits, rather than offering inclusivity as promised by our person-
4
5 centred methods.
6
7

8
9 Reflexive thinking was now leading us into an epistemological quandary of questions: Were
10
11 we in danger of catering to the dominant restitution narrative (Frank, 1995) and the idealised
12
13 healthy body (white, male and abled) (Lupton, 1994)? Were we losing alternative narratives
14
15 that depict the nuance of loss, the helplessness of illness and the 'unspeakable' pain of
16
17 experience? Is it the role of the participants, arguably those already vulnerable and suffering,
18
19 or ours as researchers, to reinterpret experiences? Do we risk paternalism by such a stance?
20
21 And does this reinterpretation say more about our own lived experience of the phenomena of
22
23 our research; that is, in decentering the author, have we instead created a solipsistic
24
25 recentering? Are we staying 'true' to their voice, and what, indeed, is truth anyway (Gadamer,
26
27 1995). Or is being polite and affable more a social role, rather than a lived one; merely a 'face
28
29 work' (Goffman, 1959; Little, Paul, Jordens and Sayers, 2002; Little, Jordens, Paul and
30
31 Sayers, 2001) for the research interaction? Were we then, as researchers being politely
32
33 agreeable, empathic indeed, in the mistaken belief we are 'witnessing' transformation, and
34
35 are participants offering up a socially desirable role of, for example, positivity, recovery, or
36
37 self-blame/responsibility? In short, how to decide on 'truth', authenticity and inauthenticity?
38
39
40
41
42
43

44
45 Given the centrality of authenticity and its connection dominant narratives, to both the
46
47 method and meaning of our paper, it is worth noting here that we use the term 'authenticity'
48
49 in the Heideggerian sense (1927/1962). It is beyond the scope of this paper for a full
50
51 discussion, suffice it to say that we consider authenticity/inauthenticity to be non-binary, not
52
53 essentialist, and not fixed in time. Nonetheless, some narratives may be merely what is
54
55 socially acceptable; relatively uncritical; perpetuate dominant ideologies and hamper
56
57 alternative discourses. At worst, inauthentic narratives disrupt and damage, and serve to
58
59
60

1
2
3 reinforce deficit models. From a research perspective, we wished to interrogate such
4
5 narratives, and consider the important concept of authenticity to be an epistemological, as
6
7 much as an experiential, hazard.
8
9

10
11 These questions raised ontological and epistemological uncertainties for the research process,
12
13 as well as questions about the implementation of policy and practice. We were left unsettled
14
15 about what we routinely co-create, wondering about the legitimacy, veracity, reliability and
16
17 authenticity of this now much vaunted process of foregrounding patient voice and experience.
18
19

20
21
22
23 (ii) Methods: Procedures

24 We draw on findings from six (Author b et.al, 2015; Author b, 2010, Author b and
25
26 Endacott, 2010; Author a, 2012, 2014, 2015) qualitative studies, all of which
27
28 explored either the experiences of mental health service users or the psychosocial
29
30 experiences of cancer survivorhood. Each study employed either narrative (author
31
32 a) or Heideggerian phenomenology (author b) and was designed to elicit the
33
34 voices and lived experiences of participants and explore existential aspects of the
35
36 phenomena under inquiry. Each study placed great store in aspects of the
37
38 interview setting that are deemed important to our locating ourselves as
39
40 researchers with integrity and to enabling as authentic a first person narrative as
41
42 possible. These include the development of rapport between interviewer and
43
44 interviewee, inviting and sustaining free-flow, uninterrupted and unrushed stories
45
46 of illness and allowing for the revision or withdrawal of narratives, with the aim
47
48 of the interview itself potentially being a restorative experience for the participant
49
50 (Frosh, 2002). We maintained a reflexive standpoint, and encouraged mutuality
51
52 of a shared dialogue, employing a critical and social justice approach to the
53
54
55
56
57
58
59
60

1
2
3 overall design of the studies. All research undertaken was ethically approved by
4
5 the universities that hosted the work.
6
7
8

9
10 We considered our methodologies, data sets and findings, although arising from
11
12 separate studies, institutions and countries, to have some startling similarities. We
13
14 scheduled a series of meetings and careful cross re-readings of our original data,
15
16 with the following aims:
17

- 18
19
20 (a) To expose our methodological assumptions about voice, lived experience and
21
22 our role as researchers; and take deeper, critical account of overlooked
23
24 asymmetrical power relations in the interview (Kvale, 2006)
25
26
27 (b) To compare and contrast our data analysis techniques and processes with the
28
29 aim of identifying assumptions, instances of asymmetrical power and collusive
30
31 practice
32
33
34 (c) To employ a post-Foucauldian analysis to our original data, in order to
35
36 reconceptualise our findings.
37
38
39
40
41
42
43
44

45 **Findings:**

46
47 In questioning whether our own values-base as researchers, which values participants/ lived
48
49 experience and subjectivity, is co-creation or collusion, we focus on three key issues and the
50
51 ways we may be:
52

- 53 (a) Normalising the inauthentic narrative within the interview/data collection process;
54
55 (b) Validating the inauthentic narrative in findings/dissemination and co-creation ;
56
57
58 (c) Reinforcing and perpetuating the dominant ideologies
59
60

1
2
3
4
5 (a) Normalising the inauthentic narrative within the interview/data collection process;
6

7 Within the psychosocial cancer care literature, there are assumptions of ‘hope and cope’ that
8 shape the ways both people with cancer (this term is used to indicated people living with and
9 beyond cancer and abbreviated to pwc) and the way practitioners describe their experiences.
10 While respecting the right of pwc to represent their experiences in whatever ways they
11 choose, conversely, the experience of cancer alone is not sufficient to provide a critical voice.
12 There are many examples of participants privileging mind over matter in magical ways,
13 perpetuating Cartesian dualism, and an embedded assumption that positivity can ward off
14 disease progression. At times there is the implication that those that die did not try hard
15 enough, or that one ’s self is to blame. These assumptions are understandable given the
16 every-day ‘mind-over-matter’ discourse about physical and mental health. There are clear
17 similarities here with the recovery and self-help literature in mental health, where staying
18 positive is given paramount importance – relegating voiced experiences of *not* feeling
19 positive, to a lesser elsewhere. Both our data sets contained numerous expressions of this
20 positivity that in subsequent readings appeared to allow no room for engagements with pain
21 far less the possibilities of death:
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39

40 I am very strong willed

41
42 I have a lot of determination, I am very independent.

43
44 It’s up to me in the end, to fight this, I can do that...

45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100
101
102
103
104
105
106
107
108
109
110
111
112
113
114
115
116
117
118
119
120
121
122
123
124
125
126
127
128
129
130
131
132
133
134
135
136
137
138
139
140
141
142
143
144
145
146
147
148
149
150
151
152
153
154
155
156
157
158
159
160
161
162
163
164
165
166
167
168
169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221
222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274
275
276
277
278
279
280
281
282
283
284
285
286
287
288
289
290
291
292
293
294
295
296
297
298
299
300
301
302
303
304
305
306
307
308
309
310
311
312
313
314
315
316
317
318
319
320
321
322
323
324
325
326
327
328
329
330
331
332
333
334
335
336
337
338
339
340
341
342
343
344
345
346
347
348
349
350
351
352
353
354
355
356
357
358
359
360
361
362
363
364
365
366
367
368
369
370
371
372
373
374
375
376
377
378
379
380
381
382
383
384
385
386
387
388
389
390
391
392
393
394
395
396
397
398
399
400
401
402
403
404
405
406
407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
452
453
454
455
456
457
458
459
460
461
462
463
464
465
466
467
468
469
470
471
472
473
474
475
476
477
478
479
480
481
482
483
484
485
486
487
488
489
490
491
492
493
494
495
496
497
498
499
500
501
502
503
504
505
506
507
508
509
510
511
512
513
514
515
516
517
518
519
520
521
522
523
524
525
526
527
528
529
530
531
532
533
534
535
536
537
538
539
540
541
542
543
544
545
546
547
548
549
550
551
552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605
606
607
608
609
610
611
612
613
614
615
616
617
618
619
620
621
622
623
624
625
626
627
628
629
630
631
632
633
634
635
636
637
638
639
640
641
642
643
644
645
646
647
648
649
650
651
652
653
654
655
656
657
658
659
660
661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770
771
772
773
774
775
776
777
778
779
780
781
782
783
784
785
786
787
788
789
790
791
792
793
794
795
796
797
798
799
800
801
802
803
804
805
806
807
808
809
810
811
812
813
814
815
816
817
818
819
820
821
822
823
824
825
826
827
828
829
830
831
832
833
834
835
836
837
838
839
840
841
842
843
844
845
846
847
848
849
850
851
852
853
854
855
856
857
858
859
860
861
862
863
864
865
866
867
868
869
870
871
872
873
874
875
876
877
878
879
880
881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935
936
937
938
939
940
941
942
943
944
945
946
947
948
949
950
951
952
953
954
955
956
957
958
959
960
961
962
963
964
965
966
967
968
969
970
971
972
973
974
975
976
977
978
979
980
981
982
983
984
985
986
987
988
989
990
991
992
993
994
995
996
997
998
999
1000

There is also, at times, dichotomous thinking; one must remain strong, positive and determined, or ‘lose the metaphoric fight (Sontag, 1990), as implied:

1
2
3 So I think you can be miserable, you can be a victim, or you can be a fighter and get on with
4
5 it

6
7
8 It's up to you. You can sit around moping or you can get up, dress up and show up...
9

10
11
12 When in the midst of suffering and uncertainty, it is understandable that unfounded
13
14 explanations create a comforting certainty:
15

16
17
18 All of the chemical and all of the pesticides and additives in our food, is a very big cause of
19
20 contribution to a lot of cancer
21
22

23
24
25 they're finding out more and more, with brain scans, and all that...that it's (depression) a
26
27 chemical thing...
28
29

30
31
32 From a methodological aspect, to take these comments and examples at face value overlooks
33
34 the social nature of interview data collection, and the need of pwc to save 'face' (Little et.al,
35
36 2001; Goffman, 1959) and the pressure on mental health survivors to be seen as coping and
37
38 'in recovery' a nebulous state increasingly defined as one in which service users
39
40 'acknowledge the inappropriateness of their 'negative' beliefs, values and behaviors' (Harper
41
42 & Speed, 2012:12). It is more socially acceptable to be healthy with food choices, for
43
44 example, positive and agentic, effectively pushing out any chaos narrative (Frank, 1995), and
45
46 the representation of alternative realities. That these stories are co-created, within the context
47
48 of a mutually respectful interview, indicates a level of trust and sharing between researcher
49
50 and participants, but even within this setting, a one-off (or short term research/researcher
51
52 engagement) can rarely encourage alternative (possibly painful and uncertain) narratives.
53
54
55
56
57
58
59
60

1
2
3 **(b) Validating the inauthentic narrative in findings/dissemination and co-creation**
4

5 When providing rich, thick data, and staying close to the participant voice, the possibility,
6 nonetheless for representing an inauthentic voice creeps in. Even if we provide exemplars we
7 are in danger of validating the dominant discourse, sometimes by virtue of what is *left out*. In
8 narrative research, for example, there is the inevitable omission of the voices of people who
9 refused to participate. Some such instances have usefully unsettled us as researchers - for
10 example the rejection (and lost possible *alternative* narrative) of one non-participant, who
11 withdrew ‘because I won’t *be that* for you’. He was referring to a petri dish, once he had
12 heard of the invitation for service users’ accounts and how they were a part of a larger
13 research initiative; or the reluctant participant whose frustration itself became the research
14 question, once he had yelled ‘this is not a clinical case study – this is my life!’ (Author a,
15 2009). In addition, the very imposition of a narrative frame on experience already masks
16 meanings. As argued by Charmaz (2002:303), the ‘raw experience of suffering may fit
17 neither narrative logic nor the comprehensible content of a story’ – and so that raw
18 experience may well be lost within the research frame.
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37

38 If co-creation is not critiqued, and decentring the author is conflated with ‘anti-expertism’,
39 researchers run the risk of validating the inauthentic or even toxic, narratives, of participants.
40 It should be noted that we do not interchange ‘toxic’ with negative, nor assume that all
41 negative narratives are critically reflective. Rather, we seek to strike a balance between
42 inclusion of multiple voices and experiences, and avoid mere relativism or dichotomous
43 thinking.
44
45
46
47
48
49
50
51
52
53

54 It is all too easy to fall back on the socially approved discourses of positivity, recovery and
55 stoicism. Minimising is a form of comfort, and making sense of the horror of the body
56
57
58
59
60

1
2
3 (Stacey, 1997). How else to describe burst bowels, breast removal, or suicide attempts and
4
5 the bleak, long painful reality of enduring mental illness? In one example of such
6
7 minimising, one participant recounted his experience of his bowel rupturing at work and
8
9 being air lifted to hospital:
10

11
12
13
14 It's not so much a terrible experience really. I don't feel unlucky or disadvantaged.
15
16

17
18 And as Lolita commented on her radical disfiguring mastectomy:
19

20
21
22 Other women had it worse than me, and it made me think how lucky I was.
23
24
25

26
27 Extracts from our corpus of first person narratives of people with severe and enduring
28
29 histories of mental ill-health also appear to be minimising experiences of trauma, crisis and
30
31 abuse adopting a 'what doesn't kill me makes me stronger' narrative.
32
33

34
35
36 The danger of validating the inauthentic, comes then, in not being sufficiently critically
37
38 interpretive of these comments for fear of disrespecting the participants lived experiences.
39
40 Indeed, research spaces and processes where disavowal of physical pain or emotional and
41
42 psychological distress is implicitly encouraged, may be contributing to a deeper problem, that
43
44 of the continued 'othering' of individuals who are not thriving, coping, smiling (Shildrick,
45
46 2002; Ehrenreich, 2010).
47
48

49
50
51 *Reinforcing and perpetuating the dominant ideologies*
52

53
54 We suggest that the fear of being perceived as negative, not fighting back, and having a
55
56 stigmatised body, unwittingly foreclosed alternative experiences of participants. The
57
58 responsibility to recover and be well may be experienced by some as an empowering spur to
59
60

1
2
3 self-efficacy, yet some participants went beyond minimising and sought to reduce exposure
4
5 to circumstances that provoked thoughts of their own mortality. When considering support
6
7 groups Ella stated:
8
9

10
11 Others have much worse experiences and you don't want to hear about that
12
13

14
15
16 and Lolita agreed:
17
18

19
20 I didn't want to join a support group as it would be too negative.
21
22

23
24 In each sample of the narratives of mental health service users there was a strong
25
26 representation of people like Tanya, who voiced the need to keep away from the 'whole
27
28 mental health group thing'.
29
30

31
32
33
34
35 Psychosocial cancer researchers are aware that fear of death and the possibility of recurrence
36
37 is a leading concern for our participants (Author b and Endacott, 2010). Again, to collude
38
39 with this normative stance would be to suggest that supportive care and life saving enhancing
40
41 information are to be avoided. As researchers, we would then be perpetuating the dominant
42
43 ideology that cancer experiences and death are to remain unseen, unheard and stigmatised;
44
45 the opposite of our intentions of including participant experience.
46
47
48

49
50
51 Within mental health research, a similar situation prevails whereby participant voice is all too
52
53 easily sequestered into either the limiting and non-agentic narrative of continued stigma;
54
55 pathology and damage, easily denigrated as autopathography - or the potentially equally
56
57 limiting and perhaps falsely agentic narrative of recovery; empowerment; and occasionally,
58
59
60

1
2
3 even epiphany through illness; voiced, in one example, (Timmy) who said mental illness had
4
5 given him:
6

7 ‘wings to fly, man...this thing [circles the head] has shown me the way...’
8

9
10 While we would not necessarily question experiences felt to be epiphanic, we do wish to
11
12 explore how space and conditions can be better created within such research for alternative
13
14 narratives, even those of silence, relegated by default to those who do not participate. It has
15
16 been argued, for example that narrative itself is a poor vehicle for expressing mental illness,
17
18 its very tendency to linearity and resolution being ‘inimical to the expression of madness’
19
20 (Stone 2004:16). First person/patient centred narrative research that perpetuates dominant
21
22 ideologies even unwittingly through its processes can, in this analysis, alarmingly constitute a
23
24 ‘kind of violence inflicted on the life narrated’ (Stone, 2004:19).
25
26
27
28
29

30 **Discussion**

31
32
33 Within the UK it is now widely endorsed that policy and mental health services embed a
34
35 recovery orientation. In England mental health policy has explicitly supported a recovery
36
37 focus since 2001 (Perkins and Slade, 2012). Within mental health research there is then,
38
39 unsurprisingly, a similar discursive pressure on research participants as that described within
40
41 psychosocial cancer research, to use the language and embedded assumptions of the strongly
42
43 normative recovery or remission paradigms. In our discussion, we consciously conflate the
44
45 recovery paradigm with the remission paradigm, similarly affected by hope and cope,
46
47 discourses integral to the neoliberal agenda (Arxer, et al. 2014). Herein we use the recovery
48
49 paradigm to include the experiences of both people with mental health issues, as well as
50
51 people with cancer, and any convergence between our participants.
52
53
54
55
56
57
58
59
60

1
2
3 The recovery discourse persuasively draws on the ubiquitous influence of positive
4 psychology and happiness science (Seligman, 2003) whilst disregarding Frank's (1995)
5 critique of the restitution narrative and its limitations. The recovery discourse appears to
6 enable an alternative to the biomedical, offering opportunities to move away from normative
7 labels such as , schizophrenic; stage 4 tumour; patient; service user; anxious, depressive. It
8 may also enable a 'quest narrative' (Frank, 1995) or 'redemption' narrative (McAdams:
9 2001:474) whereby 'the storyteller depicts a transformation from a bad, affectively negative
10 life scene to a subsequent good, affectively positive life scene'.

11
12
13
14
15
16
17
18
19
20
21
22
23 However, whilst the recovery discourse is based on principles of acceptance and resilience,
24 on strategies for living and on hope and empowerment, this apparently life affirming
25 narrative can also hold and reproduce what we termed in the findings 'inauthentic narratives';
26 that is, 'toxic stories' that enmesh both narrator and researcher in particular subject positions
27 (Sagan, 2010). Indeed participants in mental health research have alluded to this in speaking
28 of the limitations of talking therapy, and being wary and weary of fossilising illness-
29 dominated identities (Scheff, 1999; Author a, 2012). It has also been noted how personal
30 stories from within psychiatric contexts have become routinely harnessed to further the
31 interests of mental health services with some writers referring to 'patient porn' and
32 demanding that stories of resistance be reclaimed as tools for socio-political change (Costa, et
33 al, 2012). For many service users 'recovery' has also become code for cutting support and
34 coercing people into employment and indeed has been highly contested, if not entirely
35 rejected by the Mad Studies movement as a model still essentially based on an individual
36 medicalised model of mental illness (LeFrançois, et al, 2013). Harper & Speed (2012) in
37 their critique of the discourses of recovery and resilience, bring to our attention at least three
38 points regarding the infiltration of discourses of recovery. Firstly they argue that the concepts
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 of recovery and resilience are individualistic, based on medicalized and neoliberal notions of
4 individual responsibility. Secondly, they suggest that resilience discourse continues to be
5 implicitly reliant on a model of deficit, the recovery discourse reframing deficits as strengths.
6
7 Finally, they note that structural inequalities are routinely de-emphasized within the
8
9
10
11
12 neoliberal framework.

13
14
15
16 We question to what extent the ‘recovery’ discourse is yet another potentially limiting, or
17 even toxic/inauthentic narrative, not allowing language for stories of non-recovery and thus
18 losing those experiences, in a way that stories of non-compliance have been self-censored
19 from participants in the past, thus losing these multi-layered experiences too. In endorsing
20 and reproducing these problematics of recovery discourse through our own research,
21 respectful as it endeavours to be of first person experience, are we then, not colluding,
22
23 reproducing what Wright (2014) terms ‘toxic positivity’?
24
25
26
27
28
29
30
31
32
33

34 We wondered how many of the non-story tellers were burdened or ‘erased’ by pressures of
35 the recovery discourse. What happens if, for example, you are not feeling empowered? If
36 you feel that your story does not contain evangelical proclamations of resilience and new
37 found strength? That in fact, you are ill and, stuck in a bleak space where you cannot
38 communicate, reach out, share, ‘manage’ your symptoms, or even get out of bed. Then how
39 do you begin to position yourself in front of a veritable army of survivors, policy makers, and
40 professionals all chanting Recovery and Resilience or “Ra Ra Positive” (McGrath, 2004).
41
42 How much more of a ‘deficit’ is your illness now that there is, apparently, a step-wise
43 programme of recovery, and you are just not on it? So it is important to ‘hear’ the silenced
44 voices, and be mindful that one positive narrative places another in deficit.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Many of our participants had no illusion about the recurrence of mental illness or metastatic
4 cancer. Some seemed acutely aware that they shift from one side of this narrative divide to
5 the other, and swiftly. Other are caught in the liminal space of the 'waiting' room (Frank,
6 1995). They referred to the inconstancy of health, and as one participant, Poonam, put it, of
7 how 'I can say this now because I feel well...can talk to you now...that's not a given for next
8 week, or year...even for tomorrow.' Recovery, in any of its definitions and manifestations is
9 precarious. There is a tendency also, to revere one's recovery strategies, a tendency that can
10 be identified in some of the more zealous accounts; accounts which are so often those
11 endorsed within the milieu of self-help culture and positive psychology and used by the
12 media, by policy makers and advocates of the neoliberal happiness and wellbeing agenda.
13
14
15
16
17
18
19
20
21
22
23
24
25
26

27 The *responsibility* to recover and, in the words of one of our participants to 'speak well-ness'
28 may be experienced by some as an empowering spur to self-efficacy, or at the very least, as a
29 language through which to hope. Narrative health research in the past three decades has been
30 careful and instrumental in foregrounding this, and in putting the personal experiences of
31 health and ill-health squarely on the research table. Yet the lost experiences of those who fail
32 to recover; to enter remission; or even stoically narrate their journey to us as interviewers
33 may thereby be further stamped with desolation and futility. If such recovery and coping
34 narratives are perpetuated in the absence of a range of health resources the recovery
35 movement and its allied research unwittingly aligns with the neoliberalisation of healthcare.
36 In this model a withdrawal of public provision demands that individuals exercise a growing
37 ability to look after themselves and pre-supposes a healthcare system in which there is no
38 place and little affordability for the expression of existential crisis. As argued by Berlant,
39 (2011) happiness and health have become objects of political control, as the consumer culture
40 begins to demonstrate its wholesale inability to deliver these.
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Recommendations:

When the very language of resistance and user perspective is hijacked, and effectively neutered, how can the interview space and our analysis open up other possibilities? We propose that in carrying out health research, we as qualitative researchers working in the first person narrative tradition re-sensitise ourselves to how we allow for, or *disavow* emotional work (Dickson-Swift, et al 2009) in the interview space; how we enable methodological means by which to open up ‘bidirectional communication and intimacy’ (Roer-Strier, & Sands, 2015) and that we seek to expand possibilities for:

- 1) Critical longitudinal work – we consider this to be one possible way to identify subtle narrative shifts over time, and a methodological means by which to track the emergence of narratives of resistance. We acknowledge however that this work is unpopular with funders, resource-hungry and offers few ‘quick wins’ for universities highly focussed on REF(able) outputs;
- 2) Critique – With pressures on universities and their collaborations to fit the research ever more specifically to the funding it can sometimes be a tall order to embed by default a critique of the discursive/disciplinary/materialist forces contributing to narrative and subject positions within its methodology. Yet we see this as crucial even though this may herald an erosion of the status of participant-led findings;
- 3) Developing awareness of how to identify possible alternative spaces of dissent (what is not being researched; spoken about; blogged; applauded) and;
- 4) Systematically revealing how neoliberal discourses and values have saturated the academy, the impact of this on research methodology and the ways in which we think and operationalise research within HE. We advocate that Post-Foucauldian

1
2
3 governmentality analysis provides a way to address some of these epistemological
4
5 and ethical dilemmas.
6
7
8
9

10 11 **Conclusion:** 12

13
14
15 We have offered a Post-Foucauldian governmentality analysis of our own research as a way
16
17 of highlighting accidental and incidental ways in which researchers can fall into neoliberalist
18
19 ‘traps’. We have attempted to note specific ‘regimes of truth’, exploring the ways in which
20
21 various modalities of speaking the truth are formed and how empowerment in, and through
22
23 narrative research may be rhetorical, concealing a more insidious stripping of forms of power
24
25 and protection.
26
27
28

29
30
31 We found this confronting, as we consider ourselves reflexive, rigorous, and critical in our
32
33 research methodologies, but also long term adherents to the values of participatory narrative
34
35 research in health, and loyal to feminist onto-epistemological principles that put the voice of
36
37 the participant/patient/user at the heart of our research endeavour. We also acknowledge that
38
39 we, too, undertake research in Higher Education Institutions, which are also subject to
40
41 neoliberalist imperatives and engaged in their own varied struggles to reassert the university
42
43 as a place of unconditional dialogue, critique and critical resistance (Derrida, 2001.) We do
44
45 not advocate a relinquishing of the narrative interview, nor of the sensitive handling of first
46
47 person narratives in health as a means towards new knowledges, but we do argue that when
48
49 qualitative narrative research is at its best it takes as its very material the ‘unclear’ - working
50
51 the terrain of what might otherwise be lost. For this we need to focus on the ‘surplus’ that is
52
53 so irksome to positivistic research and on the very notion of the ‘outlier’ – making it become
54
55 our core business. In choosing not only to not omit the unclear and the outlier, but instead to
56
57
58
59
60

1
2
3 work with them, we may avoid the pitfall described by Heisenberg who suggested that when
4
5 research omits all that is unclear, we are left with ‘completely uninteresting and trivial
6
7 tautologies.’ (Heisenberg, 1971:213.)
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24

25 **References**

26
27
28 Andrews, M. Squire, C. & Tamboukou, M. Eds. (2013) *Doing Narrative Research* (2nd Ed.)
29 London: Sage.

30
31 Arxer, S.L., Murphy, J.W., Jung, M.C. (2014). Globalization, Market Symbolism, and
32 Coping. *Illness, Crisis & Loss*, 22(4) 333-343.

33
34 **Bauman, Z.(2007). *Liquid Times: Living in an Age of Uncertainty*. Cambridge: Polity Press.**

35
36
37 Berlant, L. (2011). *Cruel Optimism*, London: Duke University Press.

38
39 Brown, B.J. & Baker, S. (2013). *Responsible Citizens: Individuals, Health and Policy under*
40 *Neoliberalism*. London: Anthem press.

41
42 Brown, G., Pascal, J. and Western, D. (2013) Using the F-Word: Feminist epistemologies and
43 post-graduate research. *Affilia: Journal of Women and Social Work*. 28 (4) 440-450.

44
45
46 Burchell, G., Gordon, C. and Miller, P. (Eds) (1991) *The Foucault Effect: Studies in*
47 *Governmentality*. Hemel Hempstead: Harvester Wheatsheaf .

48
49
50
51 Caring for People: Community Care in the Next decade and Beyond: Policy Guidance
52 (1990). London: HMSO.
53
54
55
56
57
58
59
60

1
2
3 Chamberlain, K. (2015). Reflexivity: Fostering research quality, ethicality, criticality and
4
5 creativity. In M. Murray (Eds.), *Critical health psychology* (2nd ed.) (pp. 165-181).

6
7 Basingstoke, UK: Palgrave MacMillan

8
9 Charmaz, K. (2002) 'Stories and Silences: Disclosures and Self in Chronic Illness,'
10
11 *Qualitative Inquiry*, 8(3): 302-32.

12
13
14 Cooke, B., Kothari, U. (2002). *Participation: The New Tyranny?* London: Zed Books.

15
16 Costa, L., Voronka, J., Landry, D., Reid, J., McFarlane, B., Reville, D., Church, K. (2012).
17
18 *Recovering our Stories: A Small Act of Resistance. Studies in Social Justice*, 6, (1) 85-101.

19
20 Department of Health (1990) *Caring for People: Community Care in the Next decade and*
21
22 *Beyond: Policy Guidance* (1990). London: HMSO.

23
24 Department of Health (1991) *The Patients Charter*. DOH London.

25
26 Department of Health (1992) *Local Voices: The views of people in purchasing*, London: NHS
27
28 Management Executive.

29
30
31 Derrida, J. (2001). The Future of the profession or the Unconditional University' in: Laurence
32
33 Simmons and Heather Worth (Eds.) *Derrida Downunder*. Auckland: Dunmore Press.

34
35
36 Dickson-Swift, V., James, E. L., Kippen, S. & Liamputtong, P. (2009). *Researching sensitive*
37
38 *topics: qualitative research as emotion work, Qualitative Research*. 9 (1) 61-79.

39
40
41 Ehrenreich, B. (2001) *Welcome to Cancerland. Harper's* 303, November, 45-53.

42
43 Ehrenreich, B. (2010). *Smile or Die: How Positive Thinking Fooled America and the World*.
44
45 London: Granta.

46
47 .Ellis, C., & Bochner, A. (2000). Autoethnography, personal narrative, reflexivity:

48
49 Researcher as subject. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research*
50
51 (2 ed., pp. 733-768). Thousand Oaks, CA: Sage.

52
53
54 Fairclough, N. (2010). *Critical Discourse Analysis. (2nd Ed.)* London: Routledge.

1
2
3 Finlay, L. and Gough. B. (Eds.) (2003). *Reflexivity: a practical guide for researchers in health*
4
5 and social science Oxford: Blackwell Publishing.

6
7 Frank, A.W. (1995). *The Wounded Storyteller*, Chicago: The University of Chicago Press.

8
9 Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.

10
11 Frosh, S. (2002). *After Words: The Personal in Gender, Culture and Psychotherapy*,
12
13 Basingstoke: Palgrave Macmillan.

14
15 Gadamer, H-G. (1995). *Truth and Method* (J. Weinsheimer & D. G. Marshall, Trans. 2nd
16
17 ed.). New York: Continuum.

18
19 Goffman, I. (1959). *The presentation of self in everyday life*. New York: Random House.

20
21 Gorsky, M. (2007). Memorandum submitted to the Health Select Committee inquiry into
22
23 public and patient involvement in the NHS January 2007. History and Policy London School
24
25 of Hygiene and Tropical Medicine /Centre for History in public health, London.

26
27
28
29
30
31
32 **Hall, S. (2011): The Neo-Liberal Revolution. *Cultural Studies*,25:6, 705-728**

33
34
35
36 Harrison, S., & Smith, C. (2003). Neo-bureaucracy and public management: The case of
37
38 medicine in the National Health Service. *Competition and Change*, 7, 243–254.

39
40
41 Harper, D. and Speed, E. (2012). Uncovering Recovery: The Resistible Rise of Recovery and
42
43 Resilience. *Studies in Social Justice*, 6 (1) 9 – 25.

44
45
46 **Heidegger, M. (1927/1962). *Being and Time*. Trans J. MacQuarrie and E. Robinson. London:**
47
48 **Blackwell.**

49
50 Heisenberg, W. (1971) *Physics and Beyond, Encounters and Conversations*, New York, NY:
51
52 Harper & Row.

53
54 Hollway, W. & Jefferson, T. (2000). *Doing Qualitative Research Differently: free*
55
56 *association, narrative and the interview method*. London: Sage.

1
2
3 Hubert, S. J. (2002). *Questions of Power: The Politics of Women's Madness Narratives*.
4
5 London: Associated University Presses.

6
7 King's Fund. (2016). www.kingsfund.co.uk. Accessed 27/1/2016.

8
9
10 Kvale, S. (2006). Dominance through interviews and dialogues. *Qualitative Inquiry*, 12(3),
11
12 480-500.

13
14 LeFrançois, B. A., Menzies, R., Reaume, G. (Eds.) (2013). *Mad Matters: A Critical Reader*
15
16 *in Canadian Mad Studies*. Toronto: Canadian Scholars Press Inc.

17
18
19 Loewenthal, D. (2002). Editorial: The nature of psychotherapeutic knowledge: Psychotherapy
20
21 and counselling in universities. *European Journal of Psychotherapy, Counselling and Health*,
22
23 5, 331–346.

24
25 Little, M., Jordens, C., Paul, K., & Sayers, E-J. (2001). *Surviving Survival: Life after cancer*.
26
27 Marrickville NSW: Choice Books.

28
29
30 Little, M., Paul, K., Jordens, C., & Sayers, E, J. (2002). Survivorship and discourses of
31
32 identity. *Psycho-Oncology*, 11, 170-178.

33
34 Lupton, D. (1994). *Medicine as culture: Illness, disease and the body*. Thousand oaks: Sage.

35
36 Marston, G. and McDonald, C. (2006) "Analysing Social Policy: a governmental approach".
37
38 Cheltenham: Edward Elgar Publishing.

39
40
41 McAdams, D.P., Reynolds, J., Lewis, M., Patten, A.H. and Bowman, P.J. (2001). 'When Bad
42
43 Things Turn Good and Good Things Turn Bad: Sequences of Redemption and Contamination
44
45 in Life Narrative and their Relation to Psychosocial Adaptation in Midlife Adults and in
46
47 Students', *Personality and Social Psychology Bulletin*, 27(4): 474–485.

48
49
50 McGrath, P. (2004). The burden of the 'Ra Ra' positive: Survivors and hospice patients
51
52 reflections of maintaining a positive attitude to serious illness. *Supportive Care in cancer*,
53
54 12(1), 25-33.

1
2
3 McKee, K. (2009). *Post-Foucauldian governmentality: what does it offer critical social*
4 *policy analysis?* Critical Social Policy, 29 (3). pp. 465-486. ISSN 0261-0183.

5
6
7 Nesta. (2016). www.nesta.org.uk/2016-predications/patients-become-citizen-scientists.

8
9 Accessed 27/01/2016.

10
11 NHS England (2016). www.england.nhs.uk/ourwork/patients/. Accessed 27/01/2016.

12
13 O'Neill, O. (2002). *A question of trust*. Cambridge: Cambridge University Press.

14
15
16 Pascal, J, Johnson, N, Dickson-Swift, V and Kenny, A. (2015) Returning home: Psychosocial
17 care during the re-entry phase of cancer survivorhood in rural Australia. *European Journal of*
18 *Cancer Care*. 24 (1) 39-49.

19
20
21
22 Pascal, J, Johnson, N, Dickson-Swift, McGrath, P and Dangerfield, F (2015). Understanding
23 receptivity to informal supportive cancer care in regional and rural Australia: A Heideggerian
24 analysis. *European Journal of Cancer Care* (available first online).

25
26
27
28 Pascal, J and Endacott, R. (2010). The existential and ethical challenges of a cancer
29 diagnosis. *Journal of Medical Ethics*. 36, pp 279-283.

30
31
32
33 Pascal, J. (2010). Space, place and psychosocial well-being: Women's experience of breast
34 cancer at an environmental retreat. *Illness, Crisis, Loss*. 18, 3 pp 201-216.

35
36
37
38 Perkins, R. and Slade, M. (2012). 'Recovery in England: Transforming statutory services?'
39 *International Review of Psychiatry*, 24(1): 29-39.

40
41
42 Pilgrim, D. (2005). Protest and Co-option: the recent fate of the psychiatric patient's voice.

43
44
45 In: Bell, A., Lindley, P. (Eds.) *Beyond the Water Towers: The unfinished Revolution in*
46 *Mental Health Services 1985-2005*. Sainsbury Centre for Mental Health, London. Pp. 17-26.

47
48
49 Ribbens McCarthy, J. & Edwards, R. (Eds.) (1998). *Feminist Dilemmas in Qualitative*
50 *Research – Public Knowledge and Private Lives*. London, Thousand Oaks, Dew Delhi: Sage
51 Publications Ltd.
52
53
54
55
56
57
58
59
60

- 1
2
3 Roer-Strier, D. and Sands, R.G. (2015). Moving beyond the 'official story': when 'others'
4 meet in a qualitative interview. *Qualitative Research* 15 (2) 251– 268.
5
6
7 Rose, N. (1999). *Powers of Freedom: Reframing Political Thought*. Cambridge: CUP.
8
9
10 Rose, N., O'Mally, P., & Valverde, M. (2006). Governmentality. *Annual Review of Law and*
11 *Social Sciences*, 2, pp.83-104.
12
13
14 Sagan, O. (2009). Investigación autobiográfica y enfermedad mental: "Esto no es un caso
15 clínico. ¡Es mi VIDA!" *Historia, Antropología y Fuentes Orales* No. 41, Romper Silencios,
16 pp. 159-174.
17
18
19
20 Sagan, O. (2011). Interminable Knots: Hostages to Toxic Stories. *Pedagogy, Culture, Society*,
21 19 (1) 97-118.
22
23
24
25 Sagan, O. (2012). Heroes and Hostages: The Toll of the Bad Faith Narrative, *a/b:*
26 *Autobiography Studies*. 25 (2), 231-248.
27
28
29
30 Sagan, O. (2014). *Narratives of Arts Practice and Mental Wellbeing: Connection and*
31 *Reparation*: London: Routledge.
32
33
34 Sagan, O. (2015). "Hope crept in": a phenomenological study of mentally ill artists'
35 biographic narrative". *Journal of Mental Health*, 24 (2) 73-77.
36
37
38
39 Scheff, T.J. (1999). *Being Mentally Ill*, (3rd edition), New York, NY: Aldline de Gruyter.
40
41 Schiff, A. C. (2004). Recovery and Mental Illness: Analysis and Personal reflections
42 *Psychiatric Rehabilitation Journal* 27 (3) 212 – 218.
43
44
45
46 Seligman, M. (2003). *Authentic Happiness: Using the New Positive Psychology to Realise*
47 *Your Potential for Lasting Fulfilment*, London: Nicholas Brealey Publishing.
48
49
50
51 Shildrick, M. (2002). *Embodying the monster*. London: SAGE.
52
53
54
55 Sontag, S. (1990). *Illness as metaphor and AIDS and its metaphors* (3rd ed.). New York:
56 Picador.
57
58
59
60 Stacey, J. (1997). *Teratologies: A cultural study of cancer*. London: Routledge.

1
2
3 Stenson, K. (2005). Sovereignty, Biopolitics and the Local Government of Crime in Britain.

4
5 *Theoretical Criminology* 9: 265-287.

6
7 Stenson, K. (2008). "Beyond Kantianism - Response to Critiques", *Social Work and Society* 6

8
9 (1): 42-46.

10
11 Stone, B. (2004). 'How Can I Speak of Madness? Narrative and Identity in Memoirs of

12
13 'Mental Illness', in *Narrative, Memory & Identity: Theoretical and Methodological Issues*,

14
15 Huddersfield: University of Huddersfield, 49-57.

16
17
18 Wacquant, L. (2012). Three steps to a historical anthropology of actually existing
19 neoliberalism. *Social Anthropology*, 20 (1) 66-79.

20
21
22
23 Wright, C. (2014). Happiness Studies and Wellbeing, *Culture Unbound*, 6, 791-813.