



Love in Times of Cholera: Systemic Reflections on Supporting Families Through the Journey(s) of Illness

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This paper is the result of our increasing interest in the experience of illness in families and the concomitant reflections on how best to therapeutically support these families through this process. This interest led us to reflect on the nuanced way in which language establishes a play with the experience of illness, a play that can amplify or reduce its effects. Such an interplay in turn led us to consider the valuable role that family therapists have in helping families and treating practitioners to create a safe space for conversation about illness. Further questions are also explored in relation to whether there is a role for family therapists in facilitating the interface between our clinical practice with clients and the wider treating medical community. And, if so, what shape would such an interface take? Considerations at this level would include the anticipation of psychological reactions to diagnosis of chronic and life-threatening illnesses, in particular the importance of 'normalisation' of the psychological reactions to such chronic and/or life threatening diagnoses; the complex dynamics emerging from the interface between the effects of illness in the subjectivity of the ill person and the grief experienced by the other family members; different family members' narratives of the illness; relevant community contexts; and, lastly, ways to help the family members and/or the ill person navigate the medical system including the use of second opinions, cyberspace information, and other systems in their ecology, such as the spiritual dimension. Some aspects of children's narratives of illness are also identified. The paper has been organised around the dialogue that the authors had around one of their clinical cases.

Keywords: family therapy, systems, illness, narratives, semiotics, complexity

Key Points

- 1 The article provides an in-depth discussion of a clinical case with direct relevance to practitioners.
- 2 The article provides a good example of reflective systemic practice.
- 3 The article provides a good application of social constructionist and narrative ideas.
- 4 The article also provides post-structural considerations on diagnosis and its limitations.
- 5 The article provides a number of practical implications relevant to the field.

This paper is the result of our increasing interest in the experience of illness in families and the concomitant reflections on how best to therapeutically support families through these experiences. Miriam – Jill for the purposes of the paper – is a Clinical Psychologist and a family therapist with more than 50 years of experience and is one of the co-directors of a family therapy centre where specialised training is also offered. Jill has also been involved in providing supervision to psychologists and family therapists in a number of settings including the fields of acute and chronic illnesses. Maria – Jackie for the purposes of the paper – has close to 35 years of experience as a

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Counselling Psychologist and as a family therapist. Our interest in this area comes from a combination of professional, personal, and family experiences. Jill has been reaching GPs through the Divisions of General Practice for many years prior to being invited to the Department of General Practice of Monash University to co-author a family therapy distance program for rural GPs, some 20 years ago. These programs were described and reviewed (Jackson & Tisher, 1996; Tisher & Jackson, 2003). The experience of working with medical practitioners illuminated the complex interface between physical and mental health and the importance of addressing this complexity in a systemic framework.

The paper is unorthodox in style, knowingly so. It attempts to be recursively coherent with prevalent forms of knowledge informing the field: social constructionism (Gergen, 1985, 1999; Gergen & Davis, 1985; Gergen & Gergen, 2003) and dialogical (Bertrando & Gilli, 2008; Nichterlein, 2013; Rober, 2005, 2017). It also attempts to connect with Bateson's own use of dialogue as a pedagogical instrument and heuristic strategy (see metalogues in Bateson, 1973; Morss & Nichterlein, 1999). Rather than a straight – and often linear – narrative, the text is presented through a semi-fictitious conversation that resembles the peer supervision structure of some of our meetings. Starting with a (semi-fictitious) case, the discussion witnesses a number of themes and different lines of analysis criss-crossing, blurring the lines of disciplinary practices and aiming to bring forth a different field of understanding – or, as Bateson would say, a plateau (Bateson, 1958; see also Deleuze & Guattari, 1987)¹ – that not only escapes the limitations of lineal thinking but also invites different positions for all parties involved (including the reader).

Dialogue

Jackie: *The case*

There is a case I wanted to bring to the conversation today because, in many ways, it brings to the fore many of the issues we have been discussing in relation to chronic illness and family therapy. As you know, I work at a Child and Youth Mental Health Service (CYMHS) in a large tertiary hospital. More specifically, my work is in a brief intervention service that works with youth. Part of my role involves participating in Headspace² clinical meetings when our hospital is a part of its consortiums. It was in this setting that the case of Grace² and her family came up for discussion. They had been referred to this Headspace by a large children's hospital to address Grace's low mood. As the discussion of the referral progressed, it became clear that Grace's low mood was secondary to a rather complex clinical presentation. Grace was 16 years old and doing year 11 at the time that the family presented. Grace and her family had been living interstate until the beginning of the year. The history of Grace's illness was that Grace had been struggling for nearly 3 years with debilitating pain. For the initial 2 years, this pain was considered to be a result of constipation and being overweight. The treatment recommendations as reported by the family were simple: 'lose weight and everything will be ok.' Grace is a sturdily built teenager and her parents explained that she had always been larger than her peers in size. They did however disagree with the diagnosis, mostly because relevant assessments were not consistent with this formulation. Two years passed and the frequency of the episodes of pain increased to the extent of the family – as Grace's father stated – becoming 'furniture'

at the local Emergency department. It was only the exasperation of the parents that led the local hospital to arrange for Grace to see a gastroenterologist early last year. Once the specialist assessments were done, it became clear that Grace was suffering from a much more complex presentation and that significant organs in her body and her bodily functions were compromised (pancreas, spleen, and an unusual type of diabetes). At that time, Grace was flown to Melbourne as an emergency and stayed in hospital for a month. Her mother accompanied her. Results of examinations were inconclusive and, after a month, mother decided to return home. Unfortunately, medical follow-up where they lived was limited and, after some months, the family took the decision to relocate to Melbourne in the hope of better care. Soon after arrival in Melbourne, Grace went to hospital for another fortnight and was discharged back into the community with unclear follow-up. It was in the context of this stay that she was referred to Headspace for follow-up for her low mood and where the question as to whether it would be suitable to use antidepressants (SSRI) were considered appropriate) was raised.

Headspace had no clear information as to the status of Grace's medical condition at the time of the referral. The referral was made to address the low mood that Grace was experiencing *independently* from or in response to her medical condition, a kind of 'add on' to the medical and situational circumstances. Once the context of Grace's low mood became known (i.e., her long-term pain and complex physical condition) it became clear that Grace's referral was not appropriate because treatment at Headspace was limited to a maximum of 10 sessions per annum. In discussion with the CYMHS team, it was agreed that Grace's low mood needed to be attended by either the hospital that made the referral or by our CYMHS. It was also agreed at that time, that our brief service would have a strategic function to meet with the family whilst discussions were held as to who was to follow up Grace and her family. The purpose of our intervention was to help Grace and her family articulate their journey, understand their concerns and needs, and identify a better referral pathway for them.

Discussion

The case example is very interesting for many reasons, in particular because Grace's situation presents a complex medical mixture of well-recognised symptoms and a lack of a clear formulation and/or diagnosis that could comprehensively explain such symptoms. It sounds as if the treating medical community was unsure about the global picture of Grace's conditions, about the presence or lack of an aetiology that could account for such symptoms, whether these symptoms present a coherent constellation of one (complex) illness, or whether they are signs of a number of conditions that co-interact with each other in a complex presentation. Not surprisingly, such lack of clarity also implies a struggle to identify a clear prognosis. Recent literature might describe these symptoms as 'medically unexplained,' 'chronic functional,' or 'psychophysiological disorder (PPD)'; Clarke (2016) notes that 'millions of patients experience PPD but few health professionals have had formal training in uncovering and managing the psychosocial causes. The result is a large blind spot in the health care system' (314).

Such a complex presentation raises issues as to the meanings and the effects that emerge when rare conditions are diagnosed or when there is no diagnosis at all. What does the system do – how does it respond – when there is either no clear clinical understanding, complex comorbidity or, when events clearly show that the diagnoses

Yes, what happens when there is no clear diagnosis or diagnoses? And what if there is no clarity about the treatment path?

Jim

What is interesting from this clinical situation is that the lack of clarity around Grace's difficulties affords these perhaps more foundational dynamics to become clear. So, in a strange way, Grace's difficulties allow us to understand the presence of more layers in the complexities involved in working with people who are enduring chronic health issues, layers which have indeed become obscured when working with situations that present a clear diagnosis and clear treatment plans.

treatment can be best upheld. I agree with you. In the clinical world, we often hear about 'the success stories,' the stories where the condition had been well defined (and here the notion of 'well' is used in its double meaning: accurately and appropriately) and where the chosen treatment proved to be helpful. The moral of the story is that the client benefited from the identified intervention thus reinforcing the need to continue using such a treatment for similar cases. In this account – this storytelling – a common plot is followed. In some ways however, medical stories are more sophisticated than normal storytelling. Under the guise and guidance of science, medical stories provide abstract storylines that include 'probabilities' as part of the treatment: evidence shows this or that treatment to be more likely to be successful. But this sophistication should not blind us to the basic story structure: there is always a set of symptoms that are, firstly, organised under a diagnosis to then be treated using best practice. Even when it comes to decide on how to support people (and their families) who are experiencing some kind of illness, we – professionals and clients alike – often start with the search for a clear diagnosis that is to be followed up with the most appropriate treatment path. It is from this 'vantage point' – from this foundational discursive structure – that we then look at what we could 'add on' so that the core

Jackie

are appropriate rather than 'pathological.' In such a context, Grace's low mood and any family confusion, despair, and distress context of the referral – the experience for the client/s of 'falling down a rabbit hole.' When families or individuals are referred to us, it behoves us to comprehend the and treatment journey, which is the case for Grace and her family. describes is probably common, and amplified when there is no well-trodden diagnosis Clendinnen (2000) wrote these words 10 years after 'falling ill' – the experience she resemble this solid one, but which operates on quite different principles' (p. 1). love. It is even more like falling down Alice's rabbit hole into a world which might is the appropriate word: it is almost as alarming and quite as precipitous as falling in Inge Clendinnen (2000) describes her experience of becoming ill as: 'I fell ill. "Fall" clarity from the medical treating community, and perhaps their fear for the future? mood – to her and her family's distress about her condition, their inability to receive ing, then, should we mental health practitioners give to the context of Grace's low As you say, the referral was probably to address Grace's low mood. What mean- ing, then, should we mental health practitioners give to the context of Grace's low in the establishment of a clear path for an illness.

at hand do not explain or account for the symptoms and when the remedies are not assisting? Grace's presentation is a good reminder of our reliance on diagnosis, and its corresponding treatment, to solve problems. There is indeed a powerful cure inherent

In addition to the clarity offered by diagnosis, the commonality of the experience is also important. These difficult questions remind me of a paper written by Kathy Weingarten and her daughter, Miranda Eve Weingarten Worthen (1997). Kathy has a well-known condition – breast cancer – whilst Miranda has a rare genetic disorder. Reflecting on the experiential differences in their respective illnesses, mother and daughter note that the reality of the illness is not ‘transcendental’ – it is not an autonomous objective entity – but is a certain organisation of symptoms that is negotiated within the community of which we are a part. The meaning that emerges from such an organisation is primarily socially constructed. Unlike Grace, Miranda’s condition was diagnosed early in life and, whilst rare, it is a known and recognisable form, that is to say, it has a meaning in the medical world. But the isolation of Miranda and Grace have similarities in my mind.

In the paper, Miranda talks of her parents giving her words to help explain her experience and help her understand that it was not her fault to have this illness manifest itself in her life when she was a 9-year-old child.

The concept of blame is significant with children, especially as often they assume that the bad things that happen are their fault in some way. I find often that parents are quite surprised to find that children feel they have caused their own or their parents’ ill health. Accordingly, this is an issue that may be worth exploring in family conversations. Stating that some children or people feel they are responsible for their ill health is a way into opening this up. Families can feel relieved that this aspect is opened up. Some children have reported not only feeling that they are to blame but also feeling very afraid of stating this to anyone in the family.

In clinical practice, other family members, usually mothers but also siblings, report feeling guilty that their actions (or lack of actions) in utero or during their children’s or sibling’s lives, caused or contributed to the illness. At a systemic level, some cultures and religious beliefs also consider illness as individual or community punishment for failure to behave or believe.

In a family therapy context, creating a safe space for these fears and beliefs to be aired and heard can be very healing and enabling.

Jackie

Miranda’s story is indeed a very touching one and, as you say, it touches on many of the issues that emerge when reflecting on the existential dilemmas that life presents to Grace.

There is something disquieting when one does not have a clear understanding of the issues causing suffering. The ‘one’ here is of course a general ‘one.’ We assume that clients are already struggling and we often forget that part of the anxiety inherent to an illness is the lack of understanding, a lack that has effects not only on the clients and those who care for them, but also on the treating professionals. The power of placebos – well known in medical circles – sits here. Family therapy has also long understood the value of having ‘an explanation’ as a significant aspect of the cure. Watzlawick (1984) – referring to Allport – told the story of the power that a diagnosis of ‘moribundus’ had on the cure of an illiterate patient. Not having a diagnosis, not knowing what to expect is, in itself, disquieting and adds an extra layer – a ‘semiotic’ layer – to the suffering of the client and of the family, a layer that is not ‘physical’ yet it is as real as the physical elements of illness. Unfortunately, this is a layer that is increasingly being occluded in a medical gaze that privileges the physical over the psychological, over the sense-making that is inextricably connected with one’s sense of wellbeing.

This disquiet of not having a clear diagnosis brings to the fore this neglected dimension in the care of an illness. And this disquiet does not just sit with the family but extends also to the attitude and the activities of the medical and professional staff. The medical model (and much of the work of allied health practitioners) organises itself so as to provide a rational response to the suffering. Professionals no longer 'pray' as a main way to address an illness but, as we said before, follow a rational process where we carefully – using evidence-based practice – investigate the presenting symptoms in order to identify the causes of the suffering and reach a diagnosis that, in turn, instructs us as to the best way to treat effectively the illness in question. The nature of diagnosis is not a straight 'natural' process but one that has suffered significant changes through history. Use of a diagnosis is a powerful tool that helps practitioners in their work. Practitioners basically want to help fellow human beings in their suffering and often have to work with few resources and high anxieties. As human being themselves, they/we are open to feel vulnerable and overwhelmed. Being able to 'name' what is wrong – that is, what is underlying the suffering – becomes a powerful tool that provides some sort of solace and a compass at times to navigate the pathos. This is understandable. But it also has serious shortcomings: although powerful in terms of the demands for practitioners to work under the restraints of evidence-based practice, it often sets aside the fact that current knowledge is a highly contested field wherein there is a certain wilful blindness aimed at reducing the complexity at hand so as to make it more manageable. The medieval Blackadder joked at the medical fraternity treating most of the illnesses with leeches and perhaps civilisation will laugh equally heartily some centuries further on at the current practice of treating a vast majority of cancer diagnoses with chemotherapy.

Along similar lines, and perhaps a more direct reference to the work we do in mental health, a similar dynamic can be appreciated in psychiatry with the DSM-5 framework currently being profoundly questioned, for example, by the American National Institute of Mental Health (NIMH) taking the unprecedented decision not to fund any research which uses such a diagnostic tool (Lane, 2013), favouring instead the Research Domain Criteria (RDoC) project (Insel, 2013). The changes implied in this change of gaze are profound and it will take years before we start to see its effects. It worries me how little has been written here in Australia (and in the field of family therapy worldwide) about the implications of this change. Personally, I feel that this move to an even more 'behavioural' and 'neurological' approach has the immediate effect of narrowing the field to what is 'strictly' physical and thus, enlarging the gap with the psychological or semiotic elements that we have been speaking about.

A positive way here would be to 'seize the moment' and strategically use the lack to make it visible. Think for example of a little crack in the wall. We often forget about them and they become invisible to our eyes. But if the gap becomes so big that we 'can no longer' ignore it, then we need to do something about it. Perhaps this further reduction of what is considered 'valid' knowledge will force us to take responsibility for what is lacking.

Jill

I like your reference to the 'crack.' It reminds me of the line in the late Leonard Cohen's song 'Anthem' ... 'there is a crack in everything, that's where the light gets in' (1992). As you say, for us as mental health clinicians, seeing the crack as an enabler rather than as a fault may be important.

I also agree about the context of narratives for illness. I recall when I began practising as a psychologist in Melbourne, Australia, the thinking of the day suggested a range of causal attributes that today, 50 years later, are considered laughable and destructive. This makes me also wonder what practitioners in 50 years to come will think about our views today. For example, I recall working with autistic children at the Bouverie Clinic in the late 1960s. At that time Leo Kanner (1949) had argued that autism was associated with mothers whose children 'were kept neatly in refrigerators which did not defrost' (p. 425), suggesting that as practitioners we needed to modify mothers' child-rearing strategies to assist in the management or treatment of autism. I think back with considerable disquiet about those times, wondering how many mothers who were so worried about their children felt blamed by us as the 'experts.' Similar concerns were raised concerning homosexuality or 'emasculated sons' as caused by 'overprotective' mothers (for a review, see Breines, 1985) and schizophrenia by 'schizophrenogenic' mothers (Hartwell, 1996).

In the arena of physical health some of the language around 'fighting cancer,' 'winning' and 'losing' battles, and 'causing diabetes' has similar repercussions. The genetic narrative has come some way to changing these blame stories, but as practitioners we need to be aware of the strong undercurrents that they hold for many people in the community.

One of the aspects of living with illness that I have been thinking about recently is the group of clients I see who are trying to find language for living 'after treatment' – often with the short- or long-term side effects of such treatment(s) – and who are struggling to make sense of their lives. Some tell me that their doctors tell them that they – the clients – are writing the books on how to live after treatment because their treatments are so new that they were not expected to survive and there is no experience of long-term effects. This occurred with the HIV epidemic also, where survivors who received effective treatments had to change their narratives from accepting they were dying to finding new ways of living.

Perhaps this is a feature for Grace and her family also. Where there is no diagnosis and 'cure,' perhaps we have to learn to live with the illness and its manifestations and limitations. In the mental health field the narrative has changed in my lifetime of practice from 'cure' (promised by early psychoanalytic proponents) to management. How would a conversation with Grace and her family about management of her symptoms work? Is it better or worse than the ongoing search for diagnosis and cure? What meaning would such a conversation have for Grace and her family and for the treating community? Would it mean relief from the search or would it mean facing failure because there may be no cure?

The additional challenge for Grace is to work on a narrative that could be told to friends. This is what the Weingartens reported as significant. To have a description of one's experience and life challenges so as to increase the cultural resonance of Miranda's story and decrease the social isolation, Kathy and Miranda designed a ceremony to which Miranda's friends were invited to explain her illness, including associated negative and positive feelings. Perhaps a similar ceremony could be offered to Grace?

Jackie

Here, two further writings by Kaethe Weingarten (2012, 2013) might become relevant. In these more recent writings, she explores what she calls the 'sorrow' of living

with the changes of an enduring chronic disease, sorrows that have little recognition in modern diagnostic categories. Such a sorrow draws deeper into one's sense of self.

Jill

What you are saying also reminds me of a paper by Arthur Frank, 'Just listening' (1998). He talks of 'deep illness' and working with storytelling – deep illness is perceived as lasting and affecting virtually all life choices and decisions, and as altering identity. Deep illness is lived in the certainty that it will be permanent and the fear of this. What would Grace's story be about herself? Would she see herself as having 'deep illness?' Would she consider herself as having a 'restitution' story – 'getting sick, suffering, being treated and through treatment being restored to health?' This does not sound like it would be congruent with Grace's story at this time . . . Is Grace's story a 'chaos' story? Disability increases, pain will never remit, physicians are unable to understand and/or treat it. It is difficult to tell a chaos story. Chaos talk is 'submerged, grasping for air and it soon leaves the listeners gasping' (1998, p. 202). Our culture fears the chaos story. How do we honour the suffering that the chaos narrative implies, without accepting the remediable conditions – the lack of care – that perpetuate this suffering? (In these situations, feeling 'low' should not be pathologised but accepted as a legitimate response to an awful life . . . it is important to honour Grace's story, to honour suffering). Frank also describes a 'quest' story, where something can be learned from the condition and this learning can be passed on to others, where the teller claims the illness experience has brought about new qualities in themselves. This appears not to apply to Grace at present but maybe, some time in the future, it may?

It is also important for the therapeutic work to see the encounter as an opportunity to create space for Grace and her family to identify what has been helpful and unhelpful in their interactions with the medical community. Clients often express surprise that, as clinicians, we are interested in their perspective – this can be experienced by clients as empowering.

In the paper by Weingarten and Weingarten Worthen (1997), Miranda also spoke of doctors accusing her of not reporting her symptoms accurately and blaming her, attributing her symptoms to psychological factors. Her resilience, she reports, came from her parents advocating for her. She writes of the isolation of experience associated with illness – common to Grace also? The authors in this paper suggested three narrative concepts to 'make sense' of their experience:

- *Narrative coherence* – which is clear for a well-known condition such as breast cancer but rare conditions 'have the feeling of a deck of cards thrown into the wind.'
 - Which doctors should be consulted?
 - Are they on the edge of a cliff? Or have they already fallen over?
- *Narrative closure* – rare and undiagnosed conditions have a low degree of narrative closure: multiple gaps and virtually no cultural resonance.
- *Narrative interdependence* – rare and undiagnosed conditions have no connection to the illness of anyone else in the extended family. Again, unlike common conditions . . .

Practitioners do what they can. But what if they can't, if they don't know, or feel helpless or powerless. What do they/we do then? How do/should we communicate this 'not knowing' to our clients and families, and indeed to each other? Rolland

(1994) addressed the important context of health beliefs of clinicians, noting that these 'represent a mixture of personal, professional and institutional beliefs' (p. 150).

It takes courage and insight for all of us as treating practitioners to know when we don't know. Kasia Kozłowska (2016), when recently reflected on working with somatising children, commented on how, as a therapist, 'does one maintain one's own equilibrium in the face of "not knowing" and "not understanding"?' (p. 7).

Jackie

That is very interesting. I agree with you on the complex skills required for a therapeutic engagement with complex presentations or when the knowledge available runs to its limits and of the art involved in the nuanced ability to listen to such a complexity. Grace's complex presentation and the absence of a clear aetiology forced the medical system outside of its knowledge and comfort zone. I once was talking with a medical registrar as to what did they do if they did not have clear diagnosis. He explained that it is then that they would talk with their seniors. I persisted in the question and, after saying he did not know, he jokingly said, we would discharge them. This should not horrify us since it shows the human part of those who have to deal with suffering every day. But, notwithstanding its humanity, it highlights the effects on other parts of the system as a whole. Grace was not discharged but her appointments were left for months to come, creating a sense of limbo for the family and a sense of anger for Grace. Quite rightly, Grace's parents were expressing their frustration for having uprooted Grace and her sister to come to seek medical support and finding avoidance instead.

Jill

Indeed. And the challenge is how we can offer a space for the family to give meaning to the sense of isolation and rejection that they are feeling – perhaps also their own sense of failure. When patients don't get better, when their symptoms don't fit into established criteria and treatments don't work, they often feel they are failing – and failing to make our treating practitioners feel validated. This also extends to the broader systemic requirements and costings associated with patients who keep presenting without improvement. I recall supervising a group of practitioners who were working with people with intellectual disability. One of their issues was that an important criterion for their effectiveness was the re-attendance rate: when clients kept coming back, the bureaucracy took that to mean that the interventions were inappropriate. Bureaucratic measures would see the return of clients as a sign that the practitioners were failing. Once we identified this systemic factor in the system, the practitioners put together a submission to their superiors noting that the re-attendance of clients with intellectual disability was, in fact, a positive rather than a negative indicator and requesting a change in the performance criteria to reflect this philosophy. This request was accommodated and the experience of practitioners and clients was enhanced. The competing cost variables between the cost of early intervention and the costs incurred through long-term decompensation and institutionalisation need to be articulated.

Jackie

I agree with your comments and they make me think of the scope of the work we did with Grace and her family. Albeit a brief intervention service, the work we did

was significant in its twofold intervention. On the one hand, we worked with Grace and her family to understand not only their fears but also their questions. Some of their questions were indeed about what was happening to Grace – a diagnosis – but many were about ‘what to do.’ A simple example: ‘We are following all the recommendations given in terms of how to manage Grace’s sugar levels and they continue to be out of control. What are we missing? And, if we are missing nothing, what are we to do next?’ Questions like these had not been addressed by the treating teams. It is unclear as to whether it was because the family had not asked or because the teams had not responded. It is not about allocating cause or blame but about collaborating and about being as clear as possible in terms of what is the focus amidst the confusion. Part of the problem is that the family was carrying these doubts and there was no clear effective response that helped the family feel supported. Secondly, the work also focused on identifying which hospital would provide the psychological care that Grace and her family needed. We were clear that the problem was not ‘another’ pathology in Grace but the need for coordination and acknowledgement of the multiple dimension in Grace’s and her family’s life that were affected by her illness. Surprisingly, at least for me, although the hospital in question had four different teams working with Grace – including one coordinating the care – there was not one psychologist or family therapist working in any of these teams. The response to the distress that Grace and her family were experiencing was to bring a consult liaison registrar – yet another different team – to assess Grace. This was the assessment that led to the referral to Headspace to address her low mood, a referral that included the consideration of antidepressants. When I addressed with them the inadequacy of the referral and the desirability of having someone who could talk with the family about this complex journey, the hospital in question – despite being a large and very reputable hospital – made it clear that they did not provide such services.

Jill

This part of your comments focuses on the treating community – in my mind a very important aspect of the experience that Grace and her family have. Perhaps Grace’s family are the type of patient that make treating professionals’ hearts sink when they see their names in their appointment book. The concept of ‘heartsink patients’ stems from general medical practice and refers to patients who ‘exasperate, defeat and overwhelm their doctors by their behaviour’ (Lee, 2012, p. 455). Perhaps we need to think about the needs of treating professionals too and, as systemic practitioners, be able to recognise when they feel unable to help and the meaning this has for them. A further extension of this would be to offer clients the narrative that treating professionals can feel this way and that this is not a blaming exercise but an effect of the burden of care. Clients then could become more attuned to identifying the signs and contextualise these difficulties. Strategies for clients to open up these conversations with treating professionals may also be relevant – along the lines that the client can seek more than one opinion and that the professional is there to walk the journey with them rather than necessarily ‘diagnose and treat effectively.’

Summary and Some Practical Considerations

Unlike lineal narratives – narratives that, by their own structure, have a beginning, middle, and end – conversations and dialogue are recursive in nature and have no

clear limit. They can end in the midst of a first encounter or they can last for years, either framing the quality of the conversation to come or a theme that reverberates and/or repeats as time passes through one's existence. In this sense, the conversation in this paper could have continued well beyond, adding to the rich texture of life and love. At this point, a clarification might be needed: the title. *Love in the Time of Cholera*, as some of the readers will know, is the title of the novel in which Gabriel Garcia Marquez (1988) plays with ideas of illness and of love, murky-ing the definitions and the limits between these two critical existential concepts.

Having these ideas in mind however, there is still value in providing some temporal closure to this discussion and to reflect a bit on the territory travelled. We have done such reflection by exploring some pragmatic consequences of these insights.

The referral was to address Grace's low mood. Hypothetically, one might address this low mood by prescribing medication and/or talking therapies. These strategies might lift Grace's low mood. In this paper our conversation has taken a wider perspective however, looking at both the sense-making involved vis-à-vis Grace's symptoms – sense-making by Grace herself, her family, her and the medical community – as well as at the interface with the medical and psychological treating communities when clinical presentations prove complex. With this wider perspective of family therapy and illness narrative, and invoking the spirit of living and loving 'in the time of cholera,' here are some therapeutic considerations that might assist clients who experience some of the complexities presented by Grace and her family.

- First and foremost, as systemic practitioners, we need to be aware of the definitions and understandings that relevant parties have of the current presentation since they are central to the healing. Explicating these definitions can be done through a series of different strategies, including:
 - o In the family space or in individual sessions, offering space for Grace's narrative of the experience of the illness, including any narratives of blame that might be present. Again, validating that this is a common response would be relevant either overtly or indirectly through the process. Questions that might help such an exploration include: what are the narratives in members of Grace's family in respect to illness in general? What does it mean to be ill, what does it mean to feel helpless in the face of pain and of not being able to get answers and relief? Who else in the family or extended family can relate to these experiences? Circular questions can also be helpful, inviting Grace to imagine how other members of her family see and understand her illness. Circular questions can also be helpful in inviting family members to imagine Grace's experience.
 - o Exploration also needs to take place on their resilience in managing illness. Histories of resilience, in the preceding and current generation are to be given space as part of the current narrative: what has worked well and what lessons are to be made of what makes it worse?
 - o Inviting the family in taking a history of their experience with the treating medical community, including some assessment of what has been helpful and what has been unhelpful. This would be giving credence to the importance of context for Grace's low mood and an opportunity for language to be given to the experiences of isolation, frustration, fear, pain, and other responses to having a condition without a clear diagnosis and treatment path. Validation of this experience would be a part of this process.

- o The question of acceptance of lack of diagnosis and treatment path may be difficult to raise and, at times, may be clearly inappropriate. The focus on how they have lived with the condition to date and identifying the strengths offers a route into this possible conversation and again may be empowering. The narrative here relates to what to do when medical science is unable to assist at this time.
- There is also a need to help the family articulate their anxieties and their frustration and to identify the critical players involved. Strategies at this level include:
 - o Drawing a 'therapeutic genogram' that identifies relevant treating practitioners involved in the care, perhaps inviting a rating of what has been helpful and what has been unhelpful.
 - o The feeling that Grace and her family may have of being rejected by the medical system may also need to be given voice. Again, this needs to be done with a perspective of using the narrative to understand their helplessness and to gain some strategies to reduce the rejection pattern.
 - o To facilitate with the family a space of reflection on the situation and the experience of the medical treatment might be relevant and useful in empowering families to understand the position of medical practitioners and perhaps help the family have a better understanding of how to address practitioners in order to clarify their concerns in respectful and constructive ways. Although there is some value in talking with other professionals involved in the care directly, our interaction should be limited and should not replace the relationship families need to have with their clinicians. In our experience, the family can end up feeling as if they are excluded (and being talked about behind their backs), even if they give consent. There is also the added risk that the medical community may not be receptive, which may make them more fixed in their view and possibly blaming of the family for not taking the steps they recommended.
 - o With respect to the needs of the treating medical team, there is value in clarifying whether they would be interested in a meeting to discuss their approach to the family, perhaps review what they were happy with and what they would like to do differently. This would need to be discussed with the family and their permission sought, if indeed we were in a therapeutic relationship with the family. This approach might be consistent with Larner's (2003) 'hospitality' principle.
- The emphasis on all interventions need to move – pronto – away from pathologising the client/family into one of helping them to come to terms with the fact that they are experiencing significant health problems which the treating community is struggling to assist with. Such a struggle is not to be seen as an inadequacy by either party but a reminder that life throws at times vicissitudes that are larger than what is known and that, on those occasions – as with others that are more familiar – it is central to work together in identifying how best to support the person experiencing suffering and their families not only in effective ways but, far more importantly, in a humane and compassionate manner.
- In light of this critical consideration, perhaps the most important role that we as family therapists can take is staying with the family as they navigate the illness and the treatment path – 'walking the road with them.' This support can be very welcome in situations such as that of Grace and her family.

Notes

- ¹ A plateau is a central, yet hardly considered, concept in systemic theory that could roughly be described as a 'social field.' As a concept, it brings forward a critical differentiation from usual connotations of systems as being a totality in a transcendent – 'objective' – way. There is not a Universe but a multi-verse as Maturana and Varela (1984) would say. Or there are 1000 (and one, and two . . .) plateaus as Deleuze and Guattari would say (see Nichterlein and Morss, 2017). This critical move away from totalities to plateaus shifts systemic enquiry from an approach oriented to closed systems to one oriented to open ones.
- ² Australian National Youth Mental Health Foundation which offers up to 10 psychology consultations where the client has a Mental Health Care Plan prepared by a General Practitioner. Headspace are meant to deal with mild to moderate mental health presentations in young people aged 12 to 25 years of age.
- ³ Grace is not the client's real name but a reference to a Batesonian notion of a healthy – life-affirming – way of being within communities.

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