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INTRODUCTION

Coming to terms with a move from the ‘world of the healthy’ to the ‘world of the ill’ (Sontag, 1991) is one of the most difficult challenges we and our families are likely to confront: it shifts us from the domain of the ordinary to the extraordinary, demanding a radical re-organization of our individual, family, social and working lives.

However, our responses to illness are far from uniform. Where the symptoms do not appear to be severe, some (the ‘silent and healthy’) maintain our usual patterns of behaviour regardless of how we feel, while others (the ‘worried well’) do the opposite. Similarly, while some (‘stoics’) tend to underplay symptoms even if they might be indicative of a life-limiting condition others become fully invested in the role of a patient, even if the condition is unlikely to be serious (Lee and Dwyer, 1995).

Families appear to have a powerful influence on our physical and psychological wellbeing, an influence that is equivalent to all standard risk factors associated with illness (Campbell, 2003; Edwards and Clarke, 2004; Knafil and Gillis, 2002). For example, living in the same environment appears to increase the spread of infectious disease; the incidence of respiratory disease is higher in smoking households; and other family patterns such as exercise and diet affect health as well. In addition, research has found that our genetic make-up influences the likelihood of contracting certain conditions, as well as the ability to fight disease (Rolland, 2006; van Riper and Gallo, 2006).

Studies aimed at understanding adjustment to illness highlight the need to take account of social relationships, particularly relationships with one’s family. They indicate that negative, critical or hostile relationships have a stronger influence on health than positive relationships, and that experiences of stress (including stresses within the family) affect neuro-endocrine and psycho-immunological pathways, increasing the
likelihood of contracting particular conditions (Campbell, 2003; Smith and Glazer, 2006). Moreover, clinical reports suggest that when symptoms (particularly pain) become overwhelming, relationship to these symptoms can assume greater importance than relationships with people one is close to (Mason, 2004). It is therefore surprising that with important exceptions most interventions aimed at treating illness and health care trainings pay relatively little attention to the ways in which families are affected by and affect experiences of illness.

It is also important to note that until recently, a great deal of what was written about illness and death focused on deficit and pathology. This emphasis has helped to establish experiences of illness, disability and death as legitimate areas of study and psychological intervention. However, as with attempts to understand responses to other forms of untimely separation and disruption, war-related trauma, family violence and divorce, it has meant that insufficient attention has been paid to understanding why some people seem able to manage or even thrive in the face of adversity. Nonetheless, there are signs of a shift, as reflected in a growing body of work aimed at identifying factors that mediate risk and reduce the likelihood of a negative chain reaction developing in the face of potentially traumatic circumstances (Brom and Kleber, 2009).

These studies suggest that physical and emotional health is more likely to be compromised when adults and children are exposed to high levels of conflict and criticism; there is a history of psychological trauma; there are additional external stressors; people feel isolated; disease disrupts key developmental experiences; and there is a tendency towards rigidity or perfectionism. In contrast, resilience and healing tends to be greater when the family is cohesive, relationships are mutually supportive, the organization of the family is clear, people are able to communicate openly about the illness, there are few other stressors, caregivers have good coping skills and family beliefs are able to help people retain or regain a sense of hope (Boss, 2006; Rutter, 2006).

In an attempt to address these gaps, this book draws on systemic theory in discussing the challenges individuals and families face when confronted with illness, disability and death, and ways of intervening to help people reflect on their experience and connect with their sense of competence at times of particular difficulty. Although there are important differences between the experience of coming to terms with the disabling consequences of illness, and physical and cognitive disability that results from an accident or military action, many of the issues discussed in relation to illness are equally relevant to these situations.

This first chapter provides the framework for subsequent discussions about clinical work as it outlines the assumptions on which systemic
theory is based, how systems respond to change, the challenges associated with ambiguities in roles, tasks and boundaries, and the dynamics that underpin collaboration between medical and non-medical health care professionals. Chapter 2 provides an overall discussion of the main challenges illness, disability and the prospect of death present to individuals and their families, while Chapter 3 draws on a case example in outlining how systemic ideas and techniques can be used to help people move and connect with their sense of competence at times of particular difficulty.

The following six chapters focus on particular aspects of illness, namely the experiences of children, parents, adults and couples, illness in later life, bereavement, and the challenges migration and cross-cultural differences pose to the providers and recipients of health care. The book ends by discussing the personal–professional challenges this work tends to present and how supervision can contribute to the professional development and support of medical and non-medical professionals alike.

To illustrate how systemic ideas and techniques are applied in practice, the book draws on actual clinical experience. However, details have been altered to protect confidentiality and case examples draw on situations that have arisen over the course of the rest of my work to illustrate as wide a range of issues as possible. Although the ideas and techniques discussed here draw on my work as a family psychotherapist and clinical psychologist in a number of inpatient and outpatient health care settings and, more recently, as an independent practitioner, my experience as a supervisor and trainer suggest that they are applicable to the work of other health care professionals, including doctors and nurses.

### Introduction to systemic theory

Systemic theory emerged out of a desire to develop ideas and practices that could meet the need to work with families, to move beyond the internal world of the individual to facilitating change in relationships with people who are most significant to them, as well as in their experience of themselves. It draws attention to the centrality of relationships and communication to the development of identity and experience, opening up the possibility of recognizing the interactional ways in which problems are constructed and maintained, rather than seeing problems and ‘pathology’ as rooted in one person.

The theory has its roots in cybernetics, in the work of scientists who noticed that a wide variety of biological and non-biological phenomena
appeared to share the same attributes. This led to attempts to identify a set of principles that could account for the ways in which all systems are organized, maintained, and change in response to internal and external pressures and process information (Bateson, 1972; von Bertalanffy, 1968). Although there are obviously important differences between mechanical, biological and human systems, many of the ideas arising from this original work continue to inform current theorizing and clinical work with families, including that:

- The whole is different from the sum of its parts.
- Change to any one part of a system has a ripple effect on the rest of the system.
- Despite being members of the same system, our experiences of that system are unique.
- Systems (including family and professional systems) respond to disturbances by attempting to re-establish the status quo.
- There is a fine balance between the need for stability and the need to accommodate to change.
- Tensions are more likely to arise at times of transition.
- To understand any observations about a system, one needs to take account of the position of the observer, and the beliefs they hold.

As with all theoretical and therapeutic paradigms, systemic ideas have evolved over time. Subsequent work has moved away from the relatively mechanistic nature of the early theorizing. Although the approach continues to place emphasis on the relational nature of human experience, on interactions in the here and now, increased attention is paid to the individual’s internalized experience, including experiences of the past and the ways in which professionals’ own experiences affect and are affected by interactions with the people with whom they are working (Byng-Hall, 1985; Flascos and Pocock, 2009).

Informed by social constructionist ideas, current work is based on the assumption that there is an inextricable link between the ways in which we respond, beliefs, language and the discourses that dominate the wider context, including discourses that relate to gender, racialization, age and sexual orientation. Although these wider discourses do not determine how we respond, they inform the range of issues we draw on in knowing and deciding how to act and think. Social constructionist ideas have also led to growing awareness of the need to take account of the inequalities of power that exist within families and between the recipients and providers of health care (Benbow, 2005; Hollway, 1984; McCann et al., 2000).
Linked with this is the idea of positioning (Davies and Harre, 1999),
the idea that in all conversational interactions, we draw on various
storylines in presenting a meaningful account of our experience in
claiming, affirming, refuting and contesting the ways in which we are
positioned by others. Although these positions are not prescriptive,
they are informed by the discourses that dominate the context in which
these conversational interactions take place. Although positioning is
not necessarily intentional and the ways in which we position ourselves
and are positioned change depending on the account that is being
presented, there are rights and responsibilities associated with a posi-
tion. This means that being positioned as a patient or carer carries obli-
gations and expectations of how to behave.

Narrative theory has had a significant influence on systemic think-
ing as well, in particular the idea that experiences are mediated through
the stories we tell and are told about ourselves, and that we tend to
rework these stories as our experiences and understandings change. This
means that, even if certain stories and memories of the past are
extremely compelling and powerfully ensconced, one story or memory
is never able to embrace the full complexity of the events that take
place. As such, other stories, memories and ways of viewing experience
are always possible, even if we are unable to see this at the time
(Weingarten, 1994; White and Epston, 1990).

With this in mind, a systemic approach to working with people who
are ill, disabled and dying is based on the assumption that it is impossi-
ble to make sense of experiences of illness, disability and death without
taking account of the relationships between the various people
concerned (for example, interactions between members of the family,
with the health care professionals, friends and colleagues), past experi-
ences of illness and loss, personal and shared beliefs and the discourses
that dominate the context in which health care takes place.

However, just because we are part of the same family this does not
mean that our responses and views will be the same. Even though a
great deal might be shared, our responses, needs, expectations and
the level of support we require will differ. This means that when ill
people and their families are struggling and become locked into
patterns that are troubling to themselves and their loved ones,
systemic work involves listening and bearing witness to their distress
as well as exploring and uncovering less noticed aspects of their expe-
rience. It also means that it is important to take account of the ways
in which health care professionals deal with the feelings evoked by
ongoing exposure to people who are ill, disabled and likely to die.
How do systems work?

A useful way of understanding how systems work is by thinking in terms of a series of feedback loops, whereby A affects B, B affects C, C affects D and D affects A. These loops operate at all levels of human interaction, from the cellular to the social and political. This opens up the possibility of viewing actions that are understood to be causes as relatively arbitrary punctuations within a complex of interacting cycles. As change at any one level requires a reworking of these patterns of interaction, tensions are more likely to arise at times of transition. In health care settings, this includes times when a child is referred from a paediatric to an adult setting, when someone in the family is unable to fulfil their usual roles and when a member of staff is promoted, leaves or retires.

Anyone who works with illness and disability will be familiar with the idea that the body operates like a system so that injury to any one part of the body can have a ‘ripple effect’ on the functioning of other parts of the body. For example, an injury to the knee can affect the way in which we stand and walk, impacting on the back and other parts of the skeleton system. If these symptoms become more severe, we may have to rely more on others, affecting our sense of self, our independence and relationships with others. This notion of a ripple effect is integral to understanding the ways in which expected and unexpected change affects the person in question, relationships between family members, and organizational systems, including health care settings.

Viewing actions in this circular way means that, rather than seeing problems, dilemmas or solutions as rooted in one person, they are seen as a reflection of the interactions that take place between two or more people. These interactions include verbal as well as non-verbal interchanges, such as the messages we convey through our tone of voice, and eye contact we do or do not make with others.

This means that in paediatric contexts, instead of seeing the parent of a seriously ill young child’s outburst of anger towards the nurse entrusted with the caring for his child as indicative of his character, it needs to be understood as part of a process that involves both parties. We also need to take account of each person’s relationships and interactions with others: although this parent’s outburst of anger may be an expression of his own feelings, it may also be informed by the anger, frustration and fear of the rest of the family.

The views we hold depend on the position of the observer, and the beliefs that observer holds. With this in mind, the parent’s anger may
seem unreasonable if understood from the position of a nurse who feels she is doing her best, but from the position of a parent who feels the care their child is receiving is insufficient, that anger is likely to feel quite justifiable.

However, this interaction is likely to be informed by more than one aspect of experience: as such, the parent’s anger may reflect his attempt to assert what he sees as in the best interests of his child and the powerlessness of having to rely on others at a time of life when he might otherwise have been able to play a more significant role in caring for his child. Where the condition is terminal, feelings of powerlessness and distress are likely to relate to the feelings evoked by being unable to protect one’s child from dying. At such times, the nurse’s engagement with this father may be informed by a parallel sense of powerlessness, by the powerlessness of being unable to avert the course of the condition, the more personal fears and anxieties this evokes in her and the difficulty of maintaining a boundary between her personal and professional experience.

As outlined earlier, the beliefs we hold inform the ways in which we think and act. As health care professionals our beliefs about health care will have been informed by our trainings and clinical experience. However, they will also have been informed by more personal experiences, including experiences of loss, illness, care and dependency within our own families, and by the ideas about health and illness that dominate the context in which we live. With this in mind, in trying to understand the interchange between this parent and nurse, it is also important to take account of the beliefs of both parties, including beliefs about the roles parents and health care professionals should play when a young child is seriously ill, and the discourses that dominate the context in which this interaction takes place.

For example, if, as I have suggested, the parent in question is a man and the nurse a woman, it might be important to consider how far gendered discourses inform this interchange and the expectations they have of each other. Despite considerable shifts in the positions of men and women, in most but not all cases, mothers tend to assume primary responsibility for the care of a hospitalized child. As such, the father’s anger may relate to his difficulty in dealing with a situation in which he feels marginalized. Adding another dimension, if we were to assume that this father is from a minority ethnic group and the nurse is a white British woman, it would also be important to consider how prejudice and racialization impact on their ability to hear one another’s views, and the beliefs they have about the likelihood of being heard and respected.
If, however, we were to assume that the professional in question is a doctor, it would also be important to take account of the expectations doctors and others have of their role and positions in society. Most people turn to doctors to guide us, contain our anxiety and save lives when we are ill. Thus doctors tend to command considerable respect. Moreover, because medical consultations tend to take place on territory that is intimidating and unfamiliar to most people (in many cases, where the patient is lying in bed), these experiences can feel disempowering. This sense of disempowerment is reinforced by the fact that, although ill people are only patients in the context of illness, the terms ‘patient’ and ‘doctor’ tend to have far reaching implications for the ways in which we see ourselves and are experienced by others.

This is important to bear in mind because although it was previously assumed that a ‘good patient’ is someone who is compliant, research and clinical experience have alerted us to the risks of dependency, and the value of ensuring that patients hold on to as much of their pre-illness identity and assume as much responsibility for their own care as possible (Barlow et al., 2002; Reiss et al., 1986).

This is not always easy. For example, where an adolescent has a chronic condition, parents and professionals are often faced with balancing two or more contradictory sets of beliefs. At one level, they may recognize that helping the adolescent assume greater responsibility for their own care will allow them to act in a way that is more in keeping with what ‘normal’ adolescence entails. However, because failure to adhere with the treatment regime can result in a significant deterioration in health, this may feel too dangerous, locking them into a pattern that is uncomfortable for both parties.

Changes in membership and structure of the system

Although all systems tend to respond to these disturbances by attempting to re-establish the status quo, as they operate within the wider context and, in the case of human systems, members of that system change as they become older, the need to re-establish stability has to be balanced with the need to accommodate to change. It is therefore hardly surprising that points of transition tend to be characterized by upheaval and rethinking, as they require changes in patterns of connection (Carter and McGoldrick, 2005).

In most work settings, if an employee leaves, or indeed dies, their post would be advertised with a clear statement about the job specification and personal requirements of any applicant. However, there is
rarely any such clarity about the roles and responsibilities of the various family members, or when it might be appropriate for the rest of the family to take over the tasks that had previously lain within the domain of someone who is seriously ill, disabled or even dead.

Some systems continue to operate over a prolonged period of time, as with families, while others are formed to meet specific tasks and dismantled once that task is completed. For example, when a child has a needle phobia, the parent, child, nurse or doctor and possibly a psychologist need to work together to resolve the phobia. Once this has been achieved, that system dissolves and people have to find a way of letting go and re-grouping around other preoccupations.

However, there is often a build up in tension at such times in an attempt to delay or reverse new patterns of relationship, as these changes require a reworking of the ways in which people operate and see themselves. For example, one of the unstated ‘rules’ of most health care settings is that one needs to carry on working at the same pace even if we have been deeply affected by the experiences of the people with whom we are working, for example by situations in which a young patient has a heart attack or when problems during the birth are likely to have long-term consequences for the child’s cognitive ability. In such situations, a common response is for senior staff members to attempt to effect what has been called ‘first order change’, that is encouraging staff to return to their usual pattern of work. However, the distress evoked in these situations means that trying to underplay how one feels is not only enormously exhausting but impossible, giving rise to such behaviours as absenteeism, listlessness and difficulties in concentrating.

Another possibility is to introduce strategies that allow for the development of a structure that is more compatible with the altered circumstances, ‘second order change’. This could involve setting up a session to allow the staff group to debrief, reflect on what took place and make sense of how they feel. This is particularly valuable if the staff group or family have concerns about the quality of family or professional care that a person had received and when there is a possibility that cuts in cost, or racism, ethnicity or sexual orientation, meant that access to care was compromised.

The structure and patterns of relating will need to change as the size and functions of that system develop. For example, many organizations are established and developed as a result of the inspiration and determination of a few people. During what has been called a ‘pioneering phase’, relationships between the people who work in that project are usually marked by enthusiasm, warmth, loyalty and little formality. As the organization becomes bigger and the demand greater, there is often
some form of crisis after which guidelines are established and patterns of communication and accountability need to be clarified to enable the members of that organization to operate. These attempts to establish greater clarity often result in members of the organization feeling they are losing touch with one another and/or the recipients of the service. Where this is the case, another crisis may arise, leading to restructuring the service once more in a way that allows for a greater level of integration (Campbell et al., 1989).

If, however, the changes that develop are unacceptable, one option we have is to use our voice (Hirschman, 1970) to work towards repairing or improving relationships by communicating complaints, grievances or proposals for change. Another is to withdraw, as in leaving the organization or ending the relationship (as, for example, with divorce), or emotionally, which means investing little energy in the organization without actually leaving the system. Although withdrawing emotionally may be aimed at protecting ourselves and ensuring we have a job, as this is likely to be at odds with the aspirations we have about our work, acting in this way can feel uncomfortable and have problematic implications for the people with whom we work.

**Collaborative care and differences in clinical roles**

In every job, there are likely to be areas in which we are required to conform to prescribed constraints and others where we need to use our initiative, as at times of unpredictable crises. It can be difficult to achieve the right balance. For example, if we act too independently, we are likely to become, or appear to be, disengaged. Alternatively, if too constrained, we are unlikely to be able to respond creatively. Similarly, although certain aspects of our work are written into our job description, a great deal is not. For example, although the work of each health care professional will be integral to the effective functioning of the unit, we are likely to have different levels of power.

As outlined earlier, despite being members of the same system, our experiences of that system are likely to differ. Amongst members of the family, these differences tend to relate to such factors as age, birth order, gender, personal characteristics like academic ability and particular experiences of the past. Although these factors are applicable to health care professionals as well, other differences relate to our trainings, professional roles, areas of responsibility. These differences may mean that although we share a commitment to working with illness, we have different views about such issues as the value of direct advice, use of
technical versus colloquial language, constructions of confidentiality and what the term ‘professional boundaries’ means.

For example, there are important differences between the skills base, trainings and expectations of medical and mental health professionals. Unlike doctors and nurses, in most health care settings, mental health professionals are not usually required to be ‘on call’. However, it is important to respect the reality and constraints of illness and the ways in which health care systems operate. Particularly when working on an inpatient unit, this means being ready to fit sessions around medical procedures like scans and blood tests, and bearing mind that although it may be less burdensome to meet outpatients before or after medical consultations, they are likely to be preoccupied with the information they have just received, or anticipate hearing.

There are also likely to be times when we are required to respond fairly quickly, for example when an emergency psychosocial assessment is needed to assist doctors in deciding whether a discharge is feasible, or when a child who is needle phobic requires an injection. Because the notion of safeguarding the space that has been offered to the people with whom we are working is integral to all forms of counselling and psychotherapy, it may feel inappropriate to cancel or delay sessions that have already been set. However, refusing to do so when it is clear that our services are needed is difficult. It tends to be particularly difficult when trying to establish closer working relationships with our medical colleagues, as this can create the perception that we are uninterested and rarely available. Consequently, it is important to be open about how much time we can offer at the outset of the work and to frame the need for additional psychosocial support as an issue that belongs to the whole team.

Another important difference is that medical and mental health professionals tend to have somewhat different understandings of what confidentiality entails. With the exception of situations where an under age child might be at risk of abuse or severe neglect, maintaining a strict level of confidentiality is integral to all forms of counselling and psychotherapy. This is rooted in the idea that confidentiality is critical to ensuring that people feel able to reflect on issues they find troubling and are unable to address with others. Indeed, in some cases concerns about confidentiality mean people prefer to see someone who has no connection with the treatment team, for fear that the issues they find troubling might compromise their medical care.

In contrast, although medical professionals are also bound by a strict code of confidentiality this does not preclude sharing information with the rest of the treatment team. As such, a counsellor or psychotherapist’s
The decision to withhold information about their sessions can be seen as obstructive. Here too, although it is important to clarify the parameters of how we work at the outset, it is also important to find a compromise that does not jeopardize either aspect of care. This might include encouraging people to share some of the concerns that relate to their health with the rest of the team, or exploring the possibility of doing so on their behalf.

Moreover, with the exception of psychiatrists, and doctors or nurses who opt for a career change, mental health professionals are unlikely to have had a medical training. Despite this, in order to help people make sense of illness-related experience we need to have some understanding of the health-related concerns they are likely to face. This could involve discussing their condition, treatment and likely side effects with medical colleagues, drawing on the literature and reputable Internet sites or asking the affected person and/or family about their condition. However, although this has the advantage of recognizing their expertise and helps to ensure that we will have some understanding of the issues they see as particularly relevant, it does mean that we are unlikely to learn about issues they are unaware of and/or choose to omit. Nonetheless it is important to recognize the limitations of our role and avoid stepping into areas that lie outside of our domain.

The need to respect difference is particularly important at times of referral. The emotional intensity surrounding situations of illness means that the bonds that develop between ill people, their families and the professional tend to be strong. When we have invested time and energy in trying to help people resolve the difficulties they face, a decision to refer them on can feel like a failure and disappointment to the referrer as well as the people who are being referred. Where the referral is from a general practitioner (GP) or consultant to a mental health profession when they have been unable to find an organic cause for the symptoms people experience, it is not unusual for the recipients of their care to feel angry, disappointed and suspicious. Although it may be impossible to fully allay the feelings such referrals arouse, exploring the meanings of the referral to people concerned can go a long way towards helping all parties respect the work that has taken place, reducing the likelihood of confusions developing and sabotaging this next phase of work.

Furthermore, in choosing to work with illness, even if there is considerable respect for psychosocial work, the care of the body is prioritized. This means that as non-medical professionals, there are likely to be times when we are confronted with feelings of powerlessness and are faced with our limitations, when, for example, we are
unable to be of any help in relation to the main issue affecting people’s lives: a life threatening and debilitating illness. These feelings tend to be heightened at times of crisis, when urgent medical attention is required. Although studies of resilience attest to the importance of being able to reflect on experiences of crisis with someone who can be trusted, people are unlikely to have the mental space to do so until the crisis has abated. There are also likely to be situations where medical professionals fail to recognize or respect what is particular about counselling or psychotherapy, as talking with people is an integral aspect of most caring relationships.

As this discussion suggests, whilst recognizing differences helps to clarify what is particular about our roles and expertise, emphasizing differences tends to obscure what is shared. Conversely, although acknowledging what is shared can be a great help in establishing a comfortable working alliance with colleagues, this can be confusing if it is at the expense of recognizing particular skills and areas of responsibility.

Summary

- A systemic approach to health care is based on the assumption that change to any one part of the system is likely to have a ripple effect on relationships between other members of that system.
- This means that to make sense of experiences of receiving or providing health care, it is important to take account of the context, including interactions with family, friends, colleagues and health care professionals, as well as the beliefs of the various parties involved and the discourses that dominate the society in which health care takes place.
- Factors like differences in health care professionals’ roles, tasks and trainings means that the ideas we hold dear are different, creating misunderstandings that can be difficult to understand.
- Rather than negating differences, creative multidisciplinary work relies on a respectful recognition of differences as well as similarities and the value of alternative perspectives.
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