

BOOK REVIEW

Ian Andrew James. (2011). *Understanding Behaviour in Dementia that Challenges; A Guide to Assessment and Treatment*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-108-8.

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Introduction

For the purposes of this book, behaviours that challenge (BC) are defined as actions that detract from the wellbeing of individuals due to the physical or psychological distress they cause within the settings they are performed. The individuals affected may be either the instigators of the acts or those in the immediate surroundings. Common BCs include: hitting, screaming, excessive pacing, apathy, *etc.* The BCs often have multiple causes (e.g., physical, mental, environmental, neurological), which are moderated by people's emotions and beliefs. BCs are common and generally managed well by carers and many resolve with time. However, some problems can become chronic or risky and on these occasions specialist assistance is required in the form of biopsychosocial approaches (i.e., medical and non-pharmacological). Such approaches require a thorough assessment of the situation and then effective targeting of the causal factors underlying the behaviours. Because BCs are not diagnosable disorders, with regular and consistent underlying causes, they will always be somewhat problematic to treat. Indeed, the method of treating them appropriately will invariably require one becoming a detective and gaining detailed information about the nature of the BC and the patient. The kind of detail required and how to put it together into a coherent formulation-led treatment package is the subject of this book.

Intended audience

The book is an invaluable tool for people working in residential care services as well as commissioners and government employees. The text describes a treatment approach designed to specifically work with residents in 24-hour care. The biopsychosocial emphasis provides

essential well researched practical teaching material for tutors in the elderly care sector.

How the book is organised

This book contains eight chapters, providing theory and practical advice on the treatment of BC, using a biopsychosocial perspective. Thus, it suggests that the management of BC should take account of the combined influences of the biochemical neurological and physical changes of dementia, as well as the psychological and social features. In each of the following chapters this perspective is illustrated and expanded upon, using case examples and research data. For example, Chapter 1 examines the concept of BC, providing an overview of types of behaviours and categorisation systems. Chapter 2 examines the common causes of BCs and provides examples of assessment tools. Chapters 3 and 4 describe the current treatment strategies, discussing the pharmacological and non-pharmacological approaches. Both of these approaches have been criticised because of their poor evidence bases, with particular concerns about the problematic side-effects of medication. Chapter 5 outlines a number of different conceptual models that have been developed in the field to enhance people's understanding of dementia and BCs. By gaining better awareness, it is suggested that clinicians' assessments and treatment strategies may be improved. In the later chapters of the book, there is a greater focus on practice and service issues. Chapter 6 describes the clinical approach which the author of the volume has developed with colleagues in Newcastle, UK for working into 24-hour care settings. In Chapter 7 a number of case examples are presented, with comprehensive descriptions of the treatment processes. Chapter 8 addresses the issue of service development, drawing on the 2009 government commissioned report 'Time for Action' in which it's author calls for a radical

overhaul of BC services and treatment approaches with a move from an anti-psychotic dominated mode of treatment to one that makes better use of non-pharmacological approaches. There is a proposal to reduce anti-psychotic usage of two-thirds over a three-year period, with 11 recommendations to allow this to be achieved. The book explores the distinction between 'prevention' and 'treatment' strategies and provides advice for dealing with BCs in their acute phases.

Writing style

Although the volume consists of only eight chapters, these are clearly amplified by very clear and explanatory figures and tables. The excellent comprehensive bibliography indicates the carefully researched evidence on which the conclusions are based. Overall, the writing style is accessible.

Anti-psychotics

It is estimated, as the book documents, that 30-40% of residents with dementia develop psychosis with paranoid delusions or hallucinations at some time during the course of their illness. These experiences may be short-lived and can resolve spontaneously, but in most situations where the symptoms persist, the appropriate treatment is a short spell on an anti-psychotic. Twenty-five per cent of people with dementia in the UK are prescribed anti-psychotics, mainly for the treatment of problematic behaviours. These drugs have significant side-effects and are effective in only one in five presentations. The use of psychotropics in the treatment of BC has received a great deal of attention of late due to increasing evidence calling into question their effectiveness and major worries about their side-effects. There are now questions about whether such medications, particularly the anti-psychotics, are being used in patients' best interests. Unfortunately, these powerful tranquillisers tend to be administered when there is no evidence of a psychosis and once prescribed the drugs are typically not withdrawn. These concerns are leading to fears of litigation and worries about complaints from families and advocates. The English National Dementia Strategy was launched in 2009 and was promised £150 million to oversee its implementation. Within the 17 objectives of the strategy, we see a positive vision of what good care provision could look like. However, few of the objectives specifically address behaviours that challenge, which are major sources of carer and family distress and the reason why many people require hospitalisation or 24-hour care.

It is evident that there is a need, and a desire, to improve care practices. As the volume discusses, the move away from a medical approach to BC is not new, it has been slowly happening over the last 20 years. However, the call for change has increased of late, gaining momentum owing to concerns about the use of drugs and the need to develop effective alternatives to them. In addition and, perhaps most importantly, additional impetus

for change has come from our politicians and economists who seem to recognise that it is essential to plan for the future from both a financial and wellbeing perspective.

This book is timely because there remains a great deal of confusion regarding the treatment of BC. Many psychiatrists believe that they have been put in a difficult situation regarding the proposed restrictions on the use of medications, particularly the use of anti-psychotics. It is relevant to note, however, that psychiatrists continue to retain a lot of faith in these drugs and continue to prescribe them on a regular basis. Currently, non-medical professionals may experience a measure of confusion, because they have received little 'quality' guidance on what to offer as a practical alternative to drugs. Indeed, many of the non-pharmacological strategies suggested in the literature are preventative methods rather than treatment approaches *per se*.

The author's survey shows that the use of pharmacological agents for the management of BPSD does not appear to be favoured by the experts (the psychiatrists). They remarked that they would rather have effective and adequate nursing input and use non-pharmacological options where possible, but the scarce availability of these options is a major limiting factor for their use. There seems to be a national need for more resources so as to invest in adequate staff numbers, effective training and appropriate facilities for managing patients with BPSD, without resorting to medication.

This positive statement supports non-pharmacological approaches. However, what is needed in the field is not a monopoly by any one mode of treatment over another, rather a combined approach which makes best use of the various treatment modalities and care methodologies. To achieve this, clinicians need to think through the mechanisms by which change is likely to be achieved and then deliver the treatments accordingly. For example, take the case of Mr Jones who is both depressed and aggressive. After formulating his difficulties, our 'change mechanism' for him is to first treat his depression prior to using some behavioural strategies for his aggression. This is because his depression is currently too severe to permit him to engage in any form of meaningful relationship with either therapists or carers.

Until directives on psychological treatments are improved, we are left chiefly with medication options. However, due to their ineffectiveness, it could be argued that it is unethical to use psychotropics unless used in conjunction with a non-pharmacological approach. Pharmacological guidelines and algorithms inform us that in those situations where pharmacotherapy is considered necessary, it should be tailored to the individual. All the drugs should be carefully monitored and reviewed in order to detect side-effects and assessed regularly concerning whether the person still requires the medication and dose in question. Jackson summarises his approach to the use of medication as: start low; go slow; regular reviews; stop as soon as possible.

Thesis of the book

Many old age psychiatrists prefer to use the term behavioural and psychological symptoms of dementia (BPSD) to denote the link to dementia in their work. However, the term BPSD has been criticised because it implies the problematic behaviours are linked directly to the dementing process. This is clearly not the case because many of the behaviours are normal coping strategies used by the general population to deal with difficult scenarios.

The following aspects are emphasised within the book: BCs are problematic behaviours that cause difficulties for the person performing them, or for the setting in which they are displayed. What is perceived to be 'challenging' will differ between settings, with some onlookers being more tolerant than others. For this reason, the term 'BC' is viewed as a 'social construct'. They often reflect some form of need that is driven by a given belief. For example, the person thinks that she needs to collect her children from school or it is related to distress by coping with discomfort or boredom. BCs have multiple causes and the neurological impairment associated with dementia is just one of the numerous factors. Categorisation systems have been developed in order to group similar forms of behaviour into meaningful units. These groupings have formed the basis of treatment strategies. Owing to the complexities involved in treating chronic BCs, treatment protocols are useful management guides.

As the volume discusses, it has been suggested that BC in dementia often reflects an attempt by a person to signal a need that is currently not being met such as indicating hunger, to gain relief from pain or boredom, or is representative of an effort by an individual to get his needs met directly (by leaving a building when he believes he must go to work). Or it may be sign of frustration (e.g., feeling angry at being told he is not allowed to exit a building). In all of these situations, the actions are attempts by the individual to enhance and maintain his sense of wellbeing or to ease distress.

Over the last ten years, as the volume outlines, researchers have tried to identify different categories of BC. One practitioner has produced one of the most valid and helpful ways of differentiating between them; she distinguishes between physically aggressive acts (hitting, hair pulling); physically non-aggressive (pacing, over-activity) and verbally disruptive behaviours (shouting, repetitive questioning).

A helpful diagrammatic representation of a BC management protocol is provided as a figure within the book. It identifies the various incremental steps employed to treat problematic behaviours. The first step is the labelling of a behaviour as a 'challenge', followed by the initial attempts to resolve the difficulty by the carers. If the problems persist, an acute physical cause may be suspected, requiring an assessment from the primary care practitioner. If the General Practitioner fails to identify any infection on screening, she may suggest the referral to a specialist mental health service. At this point there are three possible responses, one pharmacological and two non-pharmacological. In terms of the former, if a discrete

clinical disorder is identified (psychosis, depression, pain, delirium), then it will be treated through the use of medication. Or, if the behaviour is so extreme or risky, the appropriate medication may be given to tranquillise or sedate the person with dementia on a short-term basis. In relation to psychological approaches, one may either offer advice after undertaking a cursory assessment, or undertake a full functional analytical treatment package. The latter approach is the most comprehensive, involving a thorough assessment and the use of behavioural charts.

In the information sharing session (ISS) all the background information collected is presented and put together with the data from the behavioural charts. Patterns are explored and detected, potential triggers elucidated, staff are encouraged to relate their experiences of the behaviour and then issues are clarified regarding these accounts. A major part of this work is done *via* careful questioning skills that help identify patterns and generate hypotheses. For example, if a BC is believed to be associated with pain, then questioning should reveal a pain-related pattern (tooth pain - problems throughout the day, perhaps more frequent when the person is eating or drinking; arthritic pain - worse in morning, or when the person is moving or being moved). If the hypothesis relates to over-stimulation, then the BC should be more common during busy times of the day, or when the telephone rings, or when lots of things are happening at the same time. It is the author's belief that the art of good questioning skills should not be under-estimated, because many hypotheses can be supported or dismissed on the basis of one or two effective questions.

The goal of the ISS is to arrive at a single unifying account of the problem (i.e., the story) and develop a plan to deal with it. The plans may include revisions of previous carer strategies that were partially successful. However, in the revised context they may require some modification or to be used more consistently. In terms of the Newcastle Model cited by the volume, the problematic behaviour is perceived as an expression of an unmet need on the part of the resident. By the end of the ISS a set of interventions and approaches will have been developed in collaboration with the staff. It is relevant to note that the therapist plays a major role in ensuring that the goals are realistic and feasible. Indeed, for each intervention the therapist is routinely instructed to employ the SMART (specific, measurable, achievable, relevant, timely) criteria with respect to the goal setting. Further discussion about the goals is presented in the section on Treatment Planning and Support.

The behaviour, vocalisation and appearance observed during an episode of BC, when combined with the background information, can be used to try to understand what is causing the problem. Part of the role of staff trainers is to try to ensure that staff empathise with the person's situation, to think what his beliefs are and what he might be thinking in that situation and to try to understand the reasons behind the BC. In other words, the aim is for staff to develop a 'theory of mind' perspective with respect to the person with dementia. The information can then be used in devising appropriate interventions.

Treatment planning and support

As the volume describes, treatment planning and support interventions are based on carers' suggestions and are developed and refined at the end of the information sharing session with the therapist's help. After the group meeting, it is the therapist's role to take away the suggestions and put them together into a coherent treatment plan. As a result, a new care plan is produced based around the problematic behaviour. The care plans are honed down to the bare essentials, because once again it is found that overly complex treatment goals are not adhered to and often not read. Over the preceding weeks the carers are supported in their implementation of the plans and the strategies are tweaked as required in order to meet the needs of the patient and also the carer. This support may take the form of advice, modelling and teaching. The key thing to note in the common treatment strategies that have been employed by the Newcastle Challenging Behaviour Team (NCBT) is the simplicity of many of the interventions which are described in Chapter 7. For example, helping the staff to communicate better with the resident, organising regular trips out of the care setting, enabling the person to exercise more choice in his/her daily routine.

Conclusion

BCs are mostly managed well by staff as part of their routine care. As such, the majority of non-pharmacological interventions are carried out by experienced carers without assistance from specialist teams. There are many psychological approaches, but few have a good evidence-base. It is important to distinguish between preventative approaches and interventions. Interventions are used to treat BCs once they have emerged. Quality interventions tend to be formulation-led strategies tailored to the specific needs of the person within the setting. They often take the form of relatively simple actions (e.g., placing a sign on a door; allowing someone to eat by him/herself rather than in a large communal room; providing access to a garden). Success in using psychological approaches is highly dependent on how well they are delivered and therefore it is important to support carers in delivering the interventions.

Several conceptual models are discussed within the book, each covering a slightly different aspect of care and having differing functions. The feature that links them all is that they have attempted to provide an understanding of people's experience of dementia: of the predisposing, triggering and maintaining factors associated with their distress. Some of the models have also outlined various protective factors that may be enhanced in order to promote wellbeing. Conceptual models are also useful in understanding the distress of carers. Evidence suggests that by achieving a better understanding of the dynamics associated with BC, carers can re-frame the BC in the context of this awareness. Armed with such understanding, carers find it easier to focus on the person rather than on

the behaviour. Due to these potential benefits, it is hoped the use of conceptualisations will increase in the area of dementia care. Other clinical areas have greatly benefited from their use and Ian Andrew James feels that health and social care could do the same. This short but informative volume is highly recommended to its target audience.

Conflicts of Interest

The author reports no conflicts of interest.