

Examining What Care Ethics Has to Offer PBS

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Abstract

PBS has continued to develop a mounting evidence base, at the heart of which sits the behavioural science which underpins assessment, planning and evaluation. The implementation of PBS, however, requires an expanded knowledge base and skillset, one which can support mediators not only to carry out behavioural support plans, but to negotiate complexity in practice settings with empathy and relational skills. The authors argue that at present the analytical tools available to practitioners do not prioritise the care and relationships which care ethics prioritises in establishing practice as caring and ethical. This article provides an overview of care ethics, argues that it is a natural fit with PBS, and offers scope for further enhancing the caring integrity of those relationships that are vital to positive, dynamic and effective behaviour support.

Key words: Positive Behaviour Support, Care Ethics, Ethic of Care, Care, Relationships, Quality of Life, Procedural Fidelity

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Historically in social care settings, people with intellectual disabilities (IDs) have often presented behaviours of concern characterised as ‘inappropriate’, ‘dysfunctional’, or ‘maladaptive’, resulting in interventions designed to fix the ‘problem’, the apparently ‘disordered’ or ‘challenging’ person (National Institute for Health and Care Excellence, 2015). Various scandals involving inhumane treatment within residential settings have been a significant driver of reform and a focus on more person-centred support (Department of Health, 2014; National Institute for Health and Care Excellence, 2015, p. 3; 2018). However, given that restrictive interventions (including physical restraints) are still legitimately authorised as part of reactive crisis interventions, there continues to be serious concern that they will become commonplace, coercive and abusive. A growing body of research supports the efficacy of Positive Behavioural Support (PBS) in reducing behaviours of concern through improvement in quality of life (Gore et al., 2013); however, significant challenges remain. PBS training is not always found to achieve expected results (MacDonald, McGill, & Murphy, 2018) and PBS plans are not always translated into practice (Brady et al., 2019). These issues are not unique to PBS; nor are the wider, socio-political factors that impact upon them.

Care ethics is a distinctive ethical perspective predicated on the critical significance of care and relationships in all of our lives (Barnes, Brannelly, Ward, & Ward, 2015a). It offers illumination of micro- and macro-level factors contributing to poor care and abuse, as well as core concepts and a language for ethical determinations related to care – including how best to respond to behaviours of concern. This paper argues that there is a natural harmony between much of PBS and the theoretical orientation of care ethics; moreover, it makes the case that incorporation of care ethics as part of the philosophical foundation of PBS would increase its efficacy, both in terms of its aims related to enhanced quality of life and in reducing poor practice and abuse.

PBS and Challenges with Implementation

PBS is an approach in the ascendancy. The body of evidence supporting the behaviour science continues to grow (MacDonald, 2016; MacDonald & McGill, 2013; MacDonald et al., 2018); its utility is acknowledged in key public policy (Department of Health, 2014) and practice spaces (British Psychological Society, 2004); and it even is being legally mandated in some territories (Grey, Lydon, & Healy, 2016). The framework comprises ten elements across three domains: values, theory and evidence base, and process (Gore et al., 2013). While these domains are clearly inter-related, the challenges noted above serve to highlight an intrinsic tension at the heart of PBS: a disjuncture between the hard behavioural science underpinning functional assessment and behavioural support

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plan design, and the sort of soft knowledge required for implementation – between ‘an intervention technology’ (Dunlap, Carr, Horner, Zarcone, & Schwartz, 2008) and the very human, caring work on the ground of ‘skilled and empathetic mediators’ (Leitch, Jones, & MacDonald, 2020, p. 4).

Such a tension is not new. Within the nursing literature, a similar debate has occurred - is it right to call caring a science, or is it better to refer to the science of caring (Turkel, Watson, & Giovannoni, 2017)? The tension here can be seen between caring as an unlimited, holistic practice, where total knowledge is unattainable, and caring as reduced to a routine ‘scripted’ support task attached to the provision of evidence-based treatments (or interventions) to a person living with a specific diagnosis (Clark, 2016). The scientist in the nursing space, much like the behaviour specialist in the PBS space, seeks objective data in order to formulate the interventions that will be packaged and subsumed within acts of care. “At the heart of PBS is the science of behaviour change and science requires observable and measurable data” (Centre for the Advancement of Positive Behaviour Support, 2015, p. 1). In this formulation, there is a fundamental divide between the data of science and human interactivity, between the work of the behavioural scientists and that of the embedded practitioners. It is one that seems to be implicitly acknowledged, with a recognition that rigidity of the elements may be perceived in an “...overly prescriptive manner that hampers rather than facilitates the development of innovative ways to provide support to those with behaviour that challenges” (Gore et al., 2013 p.20). This recognition of rigidity also may be perceived in the statement that “a plan is just a document consisting mainly of words on paper and, perhaps, ideas in people’s minds. A plan is not an end in itself; rather, it is a device to guide implementation of what is usually a complex intervention” (Gore et al., 2013 p.20).

PBS has been described as an evidence based approach (Gore et al., 2013) and an applied science (Carr et al., 2002), with its integrity assured by the competencies of specialists (Hassiotis et al., 2018). Whilst some literature has found that families and care staff can implement PBS plans effectively (Allen, Hawkins, & Cooper, 2006), the challenge of increasing “the goodness of fit between the capacity and capability of mediators and the demands placed on them by behavioural assessment and intervention procedures” (Allen et al., 2013, p. 34) is a continuing one. This challenge is currently being considered within the growing literature on procedural fidelity. “Procedural fidelity refers to the extent to which an intervention is carried out as intended; in the case of PBS or other behavioural interventions, this is likely to refer to the extent to which a behavioural intervention is carried out according to a behavioural intervention plan” (Brady et al., 2019 p. 763). Brady et al. (2019) argue that, due to the potentially life-changing outcomes arising from the manner in which such behavioural interventions are delivered, gaps in procedural fidelity

are an ethical issue. We agree and argue that expanding the philosophical and theoretical foundations underlying PBS to incorporate care ethics may support more explicit engagement with the ethical considerations inherent in PBS practice; it may also support a rethink around issues of procedural fidelity.

Care Ethics

Carol Gilligan's (1982, 1993) critique of Kohlberg's psychological theory of moral¹ development was seminal in articulating much of the fundamental thinking that has endured in what is now referred to as care ethics. In it, Gilligan reframed questions of morality to make "relational realities explicit — how to live in relationship with others, what to do in the face of conflict" (p. xiv). Her emphasis of the moral relevance of concrete circumstances and interpersonal responsibilities, as opposed to formal, abstract, impartial applications of universal principles, has relevance for understanding the challenges discussed above and will be discussed below. First, however, a brief explanation of care ethics is offered.

Care ethics is a moral theory that emphasises previously neglected moral considerations as having at least as much importance as prevailing principles of justice, rights and utility (Held, 2006). These neglected moral considerations include: the moral relevance of attending to and meeting the needs of concrete others (Held, 2006); the relevance and value of emotions as part of moral deliberation (Held, 2006); the specific (rather than abstracted) contexts within which moral decisions are made (Furrow, 2005); the unique characteristics of particular moral dilemmas (Furrow, 2005); and listening (Koehn, 1998), openness (Orme, 2002), interpretation, communication and dialogue (Parton, 2003) as morally relevant practices. Most importantly, care ethics draws attention to the moral importance of care and the relationships within which care is enacted.

A burgeoning literature is addressed to care ethics; it has been used to support research and analysis on widely diverse contexts in which care is of significant relevance, both obviously (e.g., contexts of professional care) and those less obvious (e.g., international relations) (see, for example, Barnes, Brannelly, Ward, & Ward, 2015b; Koggel & Orme, 2010, 2011). Engagement and application of care ethics have elicited important dialogue across social sciences, moral philosophy and practice-based disciplines (Barnes, 2020). Given its wide application across social sciences and practice-based disciplines, it also is referred to as an orientation or perspective (see, for example, Verkerk, 2001) – one that resonates with and helps people to articulate deeply held beliefs and motivations, but that

¹ While we acknowledge that in some traditions, 'moral' has connotations of Christianity, for the purposes of this paper, 'ethical' and 'moral' will be used interchangeably in keeping with ethical theory/moral theory.

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also supports scrutiny, re-evaluation and ethically-motivated change. Care ethics, as a moral orientation or a critical political theory, moves ethics in general from the abstract realm to the material reality in which we all live, and in so doing, changes ethics from rules and theories to contextual deliberation and practice (FitzGerald, 2020).

Care ethics invites critical consideration of care, what it is and its place in society. The dual nature of care as both an activity and disposition (Tronto, 1993) highlights underlying tension behind the simplistic rendering of care as a commodity in market terms. Carrying out the labour of care with an uncaring disposition does not yield good care; neither do caring sentiments devoid of caring actions. This raises important questions relevant to the focus of this paper around the knowledge, skills and dispositions of those tasked with enacting PBS in the direct practices of care.

Care ethics diverges from assumptions about human nature as individualistic (Sevenhuijsen, 2003). The view espoused by traditional moral theories depicts a society in which all moral agents are free and equal, obscuring the significant dependency experienced by all its members at one or more periods of their lives. Recognition that we are all dependent on care in our daily lives and that care is central to human flourishing is important due to the tendency for people who are more obviously dependent to be misrecognised, feared and denigrated (Bozalek, 2016). It is also important because maintaining the current way we think about care serves to oppress and 'other' those who directly give or receive care:

...how we think about care is deeply implicated in existing structures of power and inequality. As we currently formulate it, care functions ideologically to maintain privilege, but this function is disguised (Tronto, 1994, p. 21).

This function is possible due to its invisibility. "Care is so fundamental to our capacity to live together that we simply cannot see its significance and it becomes possible to ignore it" (Barnes et al., 2015a, p. 3). This can be seen in the insufficient attention to caring relationships in setting out the core set of overlapping values, processes, theories and evidence-based practices that comprise PBS (Gore et al., 2013), despite the centrality of care and relationships as contextual considerations for how effectively PBS is enacted.

The Ethics of PBS

According to the Centre for the Advancement of Positive Behaviour Support (2016, p. 3), "Positive Behaviour Support is ethical because it is person-centred, involves all stakeholders, including the individual, is carried out for the benefit of the individual, does not use punishment [and

is] transparent and honest” (Centre for the Advancement of Positive Behaviour Support, 2016). Arising as it did out of a profound unease with aversive behavioural modification techniques during the 1980’s and 1990’s, PBS is committed to the specification of largely proactive strategies that are non-aversive, designed to strategically manipulate antecedents and reinforcements rather than impose any direct restrictions (Allen, 2009). Latterly, its utility in reducing the use of restrictive interventions has achieved national prominence through practice guidelines (British Psychological Society, 2004), public policy messaging (Department of Health, 2014), and latterly inclusion in the new Restraint Reduction Training Standards (Restraint Reduction Network, 2020). Practitioners are encouraged to engage with the principles of biomedical ethics when evaluating the ethical impact of decisions and actions (Centre for the Advancement of Positive Behaviour Support, 2016): Will this do no harm? [non-maleficence]; Will this do good? [beneficence]; Will it respect self-rule? [Autonomy]; and Is it fair? [justice] (Beauchamp & Childress, 2009). According to Allen et al. (2011, p. 14), “Adding a values base [to PBS], such as that derived from social role valorisation, would therefore theoretically help avoid the potential unethical use of behavioural procedures and highlight the fact that the means were as important as the ends in terms of achieving behavioural change”. Neither the social roles of people with ID nor those who care for them tend to be valorised, and this can be understood via some of the analysis above. This has considerable implications for those most likely to implement PBS in their daily practices of care; for example, whereas qualifying courses in social work in the UK require explicit content to support students’ development of ethical literacy and deliberation (Scottish Social Services Council, 2019; Social Work England, 2019), social care workers are not required to have (and are therefore not supported by) similarly robust educational scaffolding.

Within the wider context, Bauman (2006, p. 86) has identified the modern tendency to ...play down the relevance of moral criteria, or whenever possible to eliminate such criteria altogether from an evaluation of the desirability (or indeed permissibility) of human actions, leading ultimately to individual human agents being expropriated of their moral sensitivity and their moral impulses being repressed.

The role of a *technical-rational* orientation, one that emphasises instrumental approaches predicated on function and technique, has been similarly criticised for obscuring the *practical-moral* dimension (or the ethical orientation towards service) of practice and problems (Moss & Petrie, 2002; Whan, 1986). Indeed, this tendency and its resultant ethical deskilling of workers was evident in a study of residential child care workers’ experiences and views of physical restraint (Steckley, 2015);

participants clearly appeared to lack the vocabulary to articulate or make sense of the visceral, 'ethical stomach ache' evident in their responses. Rather than dismiss one or the other, Ruch (2012) argues for holding both the technical-rational and practical-moral dimensions of practice in creative tension. In regards to PBS, some authors have been openly hostile towards its seemingly incongruent components, 'Like oil and water, science and values are impossible to mix completely' (Mulick & Butter, cited in Allen et al., 2011, p. 22). We find this an overly pessimistic outlook. While a technical-rational orientation within the PBS model is evident, care ethics offers a conceptual lens for enhancing PBS such that it can also more robustly hold the practical-moral dimensions of responding to behaviours of concern, as well as the relational realities of care so central to their ethical consideration.

PBS and Care Ethics

The above-mentioned harmony between PBS² and care ethics can be seen at several points of convergence. Care ethics eschews the paramountcy of the impartial application of abstract principles in determining right action. Instead, it emphasises the moral relevance of a particular person (or people) meeting the need of another particular person (or people) (often referred to as 'concrete other' to juxtapose with the abstracted nature of some hypothetical 'moral agent') – all in the context of the relationship(s). Consideration of concrete others thus requires 'a more contextual mode of judgement' (Gilligan, 1982, 1993, p. 22) where 'our responsibilities within relationships [are] the most important moral consideration' (Furrow, 2005, p. 66). An emphasis on a concrete other in his or her context is strongly present in the opening definition, where Gore et al. (2013) essentially nail PBS' colours to the mast: an individual with a life is the subject of a personalised system of support in order to enhance quality of life outcomes; achieving this requires robust consideration of the person's context, including the physical and social environment and its wider context; the relationships around the individual are tacitly acknowledged by the inclusion of stakeholder involvement and the aim of improving their quality of life outcomes as well.

A care ethics perspective moves the focus from an abstracted moral agent to the relationships within which concrete others face moral dilemmas; as a result, the importance of incorporating the response of the care-receiver becomes prominent. This was identified by Fisher and Tronto in the 1990s as a key element of care ethics (Tronto, 1993). While today this might seem

² For the purposes of this and the next section, we will be drawing on Gore et al.'s (2013) framework given their work to synthesise research and practice literature to "form the foundation for assessing the integrity of research programmes, service developments and training courses that have aligned themselves with a PBS approach" (p. 15).

obvious, the roots of including service-user voices, experiences and, more recently co-productive involvement can clearly be seen in the development of thinking and practicing sparked by care ethics. PBS also takes seriously the incorporation of the experiences and responses of the focal person, as can be seen in its opening definition, its values, its use of applied behaviour analysis and its final process (in terms of monitoring and evaluation over the long term; Gore et al., 2013).

A different point of convergence between care ethics and PBS can be understood by looking at behaviour. How behaviour is thought about and understood is centrally important from a PBS perspective; it vitally impacts on the effectiveness and ethicalness of a given intervention and the system that produces it. Care ethics is similarly concerned with how care and ethics are thought about and understood. As a recognised ethical theory, it could be incorporated as complementary, though rather than a (complimentary) evidence-based approach to intervention, its contribution is broader. In Gore et al.'s (2013) model, the ethical content is mostly tacit though strongly reflected in: (a) the aforementioned way of understanding behaviour; (b) a non-instrumental way of thinking about eliminating behaviours of concern (i.e. with the primary aim of enhancing quality of life); and (c) references to rights, inclusion, participation and values. Bringing the basis from which the ethicalness of PBS, as well as the right or wrong, good or bad of particular, concrete applications of PBS, into explicit focus allows for clearer scrutiny of the normally taken-for-granted, yet highly impactful beliefs that drive whole project. Chief among them from a care ethics perspective is that care and the relationships within which care is enacted are of significant relevance in making determinations of ethical worth. While care is implicitly reflected in the references to caregivers and support, and relationships are similarly reflected in references to quality of life and community participation, the dearth of explicit attention on either, given their absolute relevance to the physical and social context of PBS in practice, is significant. It is a clear illustration of the potential invisibility of care. The analytic lens afforded by care ethics offers both

more effective theorisation, but also the development of ethical sensibilities and skills to be applied in different practices in different contexts ... care as a normative concept that can only exist through practices embodying the values and moral principles of care is, by definition, "good". (Barnes, 2012, pp. 6-7)

Thus the medium for implementing behavioural intervention plans is care, both as a disposition and activity (Tronto, 1993). Equipping those entrusted with enacting PBS at all levels with the sensibilities and skills to deliberate on and identify good care cannot be separated from

identifying good or right in relation to PBS. One could even go so far to say that PBS, when delivered with integrity to all component parts of the framework, can be seen as a form of care.

Care and Relationships: Opportunities for Expanded Thinking

Care ethics invites a clearer focus on care and relationships as part of the ongoing evolution of PBS. Care has been defined as “a species activity that includes everything we do to maintain, contain and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment” (Tronto & Fisher as cited in Tronto, 1993, p. 103). Traditionally care has been framed as something that one person (a care-giver) does for another (the care-receiver). Tronto and Fisher’s definition immediately expands its scope. This is important because when constricted to its primal form, as exemplified in the nursing or rearing of children, care is typically uni-directional in practical terms at least. Such devotion towards another has largely been seen as natural, instinctive, even effortless, with care historically being considered the province of women (Held, 2006; Tronto, 1993). This is problematic for many reasons. Feminist scholars such as Tronto (1993) have remarked that it has long been implicated in the operation of power structures that maintain social inequality; “care has mainly been the work of slaves, servants, and women” (Tronto, 1993 p. 21) and non-nurturant care continues to be carried out “by people of lower class, racial/ethnic, and gender standing” (Tronto, 2013, p. 21). Thus, the lack of social role valorisation not just for people with ID but also for those who care for them is brought into sharper relief within this wider understanding of the devaluing of care and its attendant denigration of dependency.

Moreover, current constrictions of care imply altruism. Considered from a care ethics perspective, altruism can be seen as “dedicating oneself to others [and] can also be a way of dehumanising oneself insofar as the self-denying person is reduced, or reduces herself, to a means to an end” (Pettersen, 2012, p. 369). Care is a moral endeavour, but the removal of the self in conceptualisations of altruistic care distorts the conditions of good care and is counterproductive. A frame of care in which the care-giver never receives, and bears all the physical, psychological and emotional costs of caring without any form of recourse is unsustainable. It also obscures the mutual, bi-directional nature of caring encounters and devalues the relationships between care-givers and care-recipients. An understanding of the complexities of responding to behaviours of

concern that is grounded in this wider, socio-political context, as well as the relational, entangled realities of the care in which PBS is implemented is more likely to yield an ethical outcome.

Gilligan's (1982) concept of moral maturity can be useful in reframing the caring endeavour; it is defined as a developmental stage individuals reach when they are able to take their own and others' interests into account. Morally mature individuals are capable of providing 'mature care', which involves contending with and balancing reasoning as well as emotional sentiments in resolving ethical dilemmas. Care ethicists have further developed the thinking around what mature care looks like within the context of a relationship. At first glance, the description of mature care offered by Pettersen (2011) looks much like the biomedical ethical principles posited by Beauchamp and Childress (2009), chiefly that it amounts to the universal condemnation of exploitation and hurt [non-maleficence], as well as the universal commitment to human flourishing [beneficence]. Pettersen (2011) however usefully builds upon this, and calls for more than being disposed towards good or right. Instead, she invites an active interrogation of the ethical implications of any actions, undertaken within the context of the relationship. Rather than simply refraining from decisions or actions that may result in the infliction of harm on others, the consideration is ethically weighted towards acts of care offered within the reciprocal context only possible within a relationship. According to Pettersen (2011), mature care requires an individual to be *active* in averting or mitigating against harm, including harms to self, others and to the relationships between them. "This expanded idea of care exposes caring to be a relational process in which both the carer-giver and care-receiver participate. To prevent inflicting harm and/or to promote flourishing, these aims of caring must hold true for both the carer and the caree" (Pettersen, 2011, p. 55). Within care ethics, to care for one is to care for all.

Conclusion

Care ethics can expand the implementation of PBS interventions into an explicitly ethical undertaking grounded in everyday caring activities that are embedded within a recognised relationship – all in a way that serves PBS's *raison d'être* to improve quality of life for all involved (Gore *et al.*, 2013). As part of PBS's philosophical basis, it can provide a language more resonant with the practical-moral orientation and experiences of many care givers and infuse the PBS framework such that the practices of care are more explicitly reflected in its values, theories, evidence base and processes.

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