

## RESEARCH ARTICLE

# The glue that keeps everybody together: Peer support in mothers of young children with special health care needs

Robin L. Dodds<sup>1</sup>  | Tanis J. Walch<sup>2</sup> 

<sup>1</sup>Division of Special Education and Counseling, California State University, Los Angeles, Los Angeles, California, USA

<sup>2</sup>Department of Education, Health and Behavior Studies, University of North Dakota, Grand Forks, North Dakota, USA

**Correspondence**

Robin L. Dodds, Division of Special Education and Counseling, California State University, Los Angeles, 5151 State University Dr., Los Angeles, CA 90032, USA.

Email: [rdodds@calstatela.edu](mailto:rdodds@calstatela.edu)

**Abstract**

**Background:** The first years following diagnosis may be particularly challenging for parents and peer support from other parents of children with special health care needs may buffer their stress.

**Methods:** This qualitative interview study sought to explore the impact of early access to parental peer support and whether it leads to positive adaptation and improved family well-being.

**Results:** Five mothers of young children with special health care needs from peer support organizations in two northern US states participated in interviews by telephone or Zoom. Themes of interest included professional scrutiny, going through the motions, someone who understands, learning and sharing, and one size does not fit all. Although most participants attributed positive changes in their emotional well-being to the support they received, they were wary of extending the impact of peer support to their child and family.

**Conclusions:** Implications for practice include embedding peer support programmes in neonatal care units and children's hospitals, as well as the addition of mindfulness practices to facilitate parental adaptation to disability and promote family well-being.

**KEYWORDS**

children with disabilities, Early Intervention, parents, peer support, qualitative research methods

## 1 | INTRODUCTION

A good deal research has been published on the negative impacts of caring for a child with a disability including stress, depression and marital strain (Hartley et al., 2011; Kearney & Griffin, 2001; Ketelaar et al., 2008). It has been suggested that the first few years may be a particularly challenging period for parents of children with disabilities (Baxter et al., 1995). The shock of diagnosis, navigating systems of care, scheduling Early Intervention (EI) providers and behaviour that challenges can lead to a pile-up of demands and stressors without

adequate resources. However, it is known that most parents exhibit resilience over time and peer support from other parents of children with disabilities may buffer the stress of caregiving and promote adaptation (Peer & Hillman, 2014).

Support providers for peer support programmes like Parent to Parent (P2P) share a positive focus on life, their abilities and their children, imparting a sense of belonging and empowerment (Dodds & Singer, 2018). This is in contrast to information and suggestions received from professional service providers, which can be perceived as negative and deficit oriented (Hastings et al., 2002).

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However, it is unknown whether parents who receive peer support during their child's EI period reap the full benefits of family-centred care, adaptation to their child's disability and improved family functioning. Most research on family-focused care has measured benefits to the parent receiving support and has not established whether these impacts extend to the family unit (Turnbull et al., 2007).

## 1.1 | Theoretical framework

The Family Adjustment and Adaptation Response (FAAR) Model was developed by Patterson (1988) to link family stress theories and resilience perspectives relevant to the study of families of children with disabilities or special health care needs. This model describes the active processes engaged in by families to balance family demands with capabilities as they move towards a state of adjustment or adaptation (see Figure 1). Demands can be everyday stresses or significant incidents. Capabilities can include tangible resources (e.g., financial), psychosocial (e.g., social support) or specific coping behaviours such as reframing. Demands and capabilities can come from an individual family member, the family unit or a community context and are understood and derive meaning by way of the family's beliefs about their family identity and world view (Patterson, 1988). The diagnosis of a young child with a disability or chronic health condition can increase demands on a family (i.e., caretaking, medical appointments and in-home early intervention visits) and challenge their belief system, leading to an imbalance or crisis. In order for a family to arrive at a state of adaptation, their world view may need to change, and members will need to accumulate new resources and appropriate coping behaviours (Patterson, 2002).

The importance of family well-being for the development of children with disabilities or special health care needs is frequently used as a justification for the need to provide family-focused early intervention services (as evidenced by the Individualized Family Support Plan) and social support. Guralnick (2011) posited that, 'the central task of EI is to establish or restore family patterns of interaction to as optimal a level as possible' (p. 20), indicating a goal to balance of demands and capabilities. A related term, 'family quality of life', has been conceived as a useful proxy measure of adaptation to a child's disability rooted

### Key messages

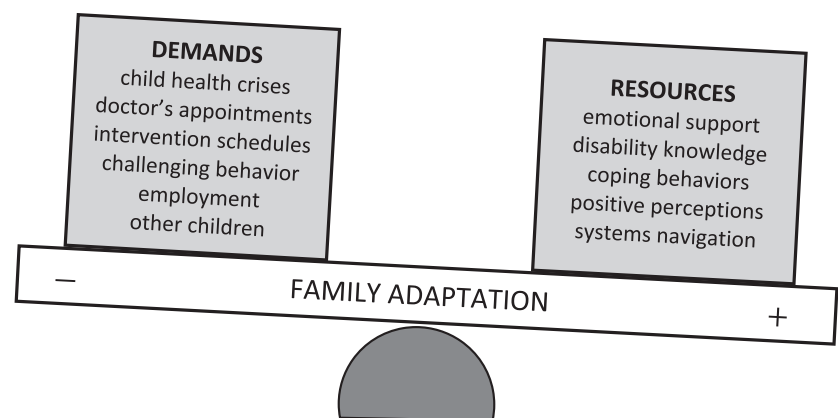
- Parents of very young children with disabilities experience heightened stress and a lack of resources.
- Peer support from a parent with a similar child can provide information and resources to support coping.
- NICU, children's hospitals and Early Intervention programmes should refer parents to peer support programmes in their area.

in positive psychology, where the return of family balance in terms of needs and resources is theorized as the entry point to developing positive adaptation (Turnbull et al., 2007).

## 1.2 | Parent to Parent

P2P is a grass-roots peer support programme developed in the 1970s that matches trained volunteer support parents with parents in need of support. P2P programmes are currently available in 38 US states, the District of Columbia and US Territories, which collectively make about 9000 peer support matches annually (Parent to Parent USA, 2019). Support parents receive 4 to 10 h of training in small groups, led by a P2P programme coordinator (who also makes the peer matches) on topics including active listening, cultural competence, how to share their story, confidentiality and locally available resources (Dodds, 2015). The help-seeking and support parent are matched along several criteria so that the parent receiving help and the parent providing support have children and experiences that are very similar.

The match then communicates by phone, with the supporting parent calling the parent seeking support the first time to reduce the burden to get help and ensure a connection is made (Dodds, 2015). According to P2P best practices, at least four contacts should be made between the matched parents over the first 2 months of the relationship, as it was found in a 1999 evaluation of the P2P programme that this number of contacts or more led to the best outcomes for the



**FIGURE 1** Family Adjustment and Adaptation Response Model (adapted from Patterson, 1988)

parent receiving support (Singer et al., 1999). It is common for parent matches today to contact each other in a number of ways including text messages, Facebook, video calls and emails in addition to telephone calls, but alternate communication methods have not been evaluated for effectiveness and formal guidelines for their use have not been issued (Dodds, 2021). P2P support has been shown to be effective in helping parents address the immediate challenges that lead them to seek support, view their current situation more positively, reduce stress and isolation, improve parent knowledge of their child's disability and services and supports available, and impart a sense of positivity (Dodds & Singer, 2018; Singer et al., 1999). Additionally, over time many parents who receive support from a P2P match go on to volunteer as support providers themselves and may enter paid service to the disability community at large (Dodds & Singer, 2018). It is not known however whether a one-to-one peer support relationship delivered during the child's developmental period (birth to 3 years of age) provides noticeable benefits to the family, beyond those perceived to support the immediate stress-reduction of the parent receiving the support.

### 1.3 | Purpose

This study sought to better understand early access to P2P support and its possible impacts on parents, their young children with disabilities and their families.

## 2 | METHODS

The study used a qualitative methodology with in-depth interviews conducted by video conference or telephone. All study procedures were approved by the University Institutional Review Board prior to data collection.

### 2.1 | Participants

A purposive sample was recruited emailing a flyer to two P2P programmes in the Northern United States who work closely with their state EI programmes. The recruitment flyer contained a link to an online survey to determine eligibility and record basic demographic information. In total, 17 parents logged into the survey and 5 participants met all inclusion criteria: They were the parent of a child with a disability under 5, had received support from P2P while their child was receiving EI, and it had more than 9 months since their initial P2P match.

All participants were White women with an average age of 40.6 years, and four were married. As shown in Table 1, participants varied on their current level of employment and highest educational attainment. Three participants first received P2P support

while their child was in the neonatal intensive care unit (NICU), and two received a P2P match later on while receiving other family-focused services for their child. The participants' children were between 3 years, 4 months and 3 years, 11 months at the time of interview. The children displayed diversity in diagnoses and services received.

### 2.2 | Data collection

All parents were informed of the study purposes and procedures and provided verbal consent to participate. A flexible interview guide was developed by both authors with open-ended questions focused around their experiences around the time of their first connection with a P2P supporter, communication with the P2P supporter and perceived benefits of P2P support for themselves and their family. Interviews were audio-recorded with the exception of Participant 5, for whom recording failed. Detailed interview notes were kept and analysed in place of a transcript for this participant. All other interviews were transcribed verbatim and verified against recordings for accuracy.

### 2.3 | Data analysis

The transcripts were anonymized and a reflexive thematic analysis was performed (Byrne, 2021). The researchers independently familiarized themselves with the transcripts by reading and rereading and taking notes throughout this and each following step. Next, succinct initial codes were generated recursively keeping close to the raw data and utilizing participant terms and applied by the first author across the entire data set. Initial codes were then collated around central organizing concepts to form emergent themes, which were reviewed and checked in an iterative process, comparing possible themes to coded excerpts in the context of the entire data set (Braun & Clarke, 2019). The authors then employed investigator triangulation by collaborating to refine codes and discuss themes until a clear narrative was developed (Braun & Clarke, 2006). While we had aimed to continue interviews until we had reached thematic saturation, the final number of participants (five mothers) was determined by challenges to availability of respondents when recruitment ceased during the summer months. Nonetheless, significant repetition of concepts was noted in the rich data collected, suggesting adequate sampling appropriate to the exploratory nature of this research (Staller, 2021). Five thematic categories were identified: professional scrutiny, going through the motions, someone who understands, learning and sharing, and one size does not fit all. Common challenges were noted, with similar experiences of disruption to and rebalancing of needs and resources by way of social support and knowledge acquisition. Categories will be discussed and illustrated with verbatim extracts from the interviews in Section 3.

TABLE 1 Characteristics of participants and their children

Age (years)	State	Rel.	Education	Employment	Child gender	Child age (months)	Diagnosis/es	Services received	Introduced to P2P	P2P calls (first 2 months)
P1	PA	Married	Professional degree	Stay at home parent/caretaker	Female	47	Pyruvate dehydrogenase complex deficiency	OT, PT, SPL, music therapy, playgroups, vision therapy, hearing therapy	3 years old	5 or more + many text messages
P2	WI	Married	4-year degree	Full-time paid	Female	41	Down syndrome (foster to adopt), congenital heart defect (repaired), pulmonary hypertension	OT, PT, speech, ECSE	Before child turned 1	1 or 2
P3	PA	Married	2-year degree	Part-time paid	Female	47	Complications of extreme prematurity, kidney disease, tracheotomy tube and congenital heart defect (repaired)	Hearing, speech, vision, PT and pre-school teacher (all homebound)	In NICU	5 or more
P4	PA	Married	Professional degree	Full-time paid	Male	47	22Q11.2 deletion syndrome, cerebral palsy	Neurology, endocrinology, immunology, orthopaedics, PT, OT, special instruction, outpatient speech	In NICU	5 or more
P5	PA	Never	married	4-year degree	Stay at home parent/		caretaker	Female	40	Dystonia/unknown cause
			Outpatient and in-home therapies, dart	movement therapy, hippotherapy	In	NICU	2++ text messages			

Abbreviations: ECSE, early childhood special education; NICU, neonatal intensive care unit; OT, occupational therapy; P2P, Parent to Parent; PT, physical therapy; Rel., relationship status.

## 2.4 | Positionality

Both authors of this study are the parent of a child with a special health care need and have been the recipient and provider of parent-to-parent peer support. They also are active in leadership for state and national organizations that serve families of children with disabilities and special health care needs across the lifespan. The researchers were careful to reflect on their roles within the community of participants and consider how they could influence interpretations of interview data (Noble & Smith, 2015).

## 3 | FINDINGS

### 3.1 | Theme 1: Professional scrutiny

This first theme was focused on stressful events of parents managing health challenges, working with service providers and receiving medical news. A common experience was the close examination of their child's body as part of the diagnostic process. Participant 1 describes her first experience with a genetic counsellor by saying, 'They ... measure their nipple space. They look at their feet and their fingers.' Participant 4 shared a similar experience immediately after birth, when the obstetrician noticed the newborn's club feet and bifid uvula, and 'wanted to take him into the nursery to give him a good exam under the lights'. The child was then transferred to a nearby NICU and diagnosed with a genetic condition. Participant 3 has a daughter with a mitochondrial disease so rare that she is 'one of a kind'. The fact that 'specialists wanted to study her' was concerning to this parent, who decided to discontinue participation in a hospital-based medical research study 'because she's not an experiment'.

Participant 2 did not experience the diagnostic process with her adoptive daughter with Down syndrome, as she became her caretaker when she was already a few months old; however, she did struggle with frustration early in her daughter's care, as health care priorities meant that her baby's development lagged further behind peers. She expressed her frustration with professionals giving conflicting advice:

[You have] a birth to three team that wants you to work on things and doctors that want you to work on things and you feel like they don't always necessarily agree. And they're saying, Oh, let's do tummy time! But we have a g-tube that's not healing and my baby's crying in pain.

Due to these early experiences, she often felt disempowered and judged by professionals but had few other resources for discussing her child's needs.

### 3.2 | Theme 2: Going through the motions

Participants all reported periods of high stress early on in their journey, whether a traumatic birth experience, sudden or chronic health crisis, or unexpected diagnosis. Because P2P programmes are often embedded in NICUs, several parents interviewed were referred to the service during their child's NICU stay.

Participants also revealed that there were periods early on prior to their connection to P2P when they struggled with their mental health. When discussing her child's early health challenges, Participant 4 said, 'I got diagnosed with major depression ... I had to admit that I wasn't Superwoman.' Participants also expressed that they were frequently fearful and lacked social support in caring for their infant with special health care needs. Participant 2 described how she felt at this time, '[Y]ou're afraid to go anywhere if you don't want her to get sick, but then you don't necessarily want to be in the house 24/7.' Participant 5 also expressed feeling isolated because her partner was working many hours, leaving her full responsibility for their daughter, and did not want to listen to her worries after a long day. This contributed to her becoming 'obsessed' with 'figuring out' her daughter's diagnosis, staying up late researching symptoms on the internet and getting little sleep, compounding her mental health challenges.

Mothers in the study also shared positive outcomes from receiving both informal and professional care for their mental health. Participant 5 worked with a therapist to learn to 'let go' of unrealistic ideals of 'what a mother should be' and to accept that she is doing her best for her daughter and her family. She now makes it a priority to include her partner in intervention sessions and doctors' appointments as frequently as possible so that the care burden is more equal. Participant 3 shared her newfound philosophy towards life saying, 'I try to take it one day at a time.' Further, in response to a question about how P2P support helped her child and family, she described an indirect benefit by way of her improved positive outlook being a model, allowing her to be 'the glue that keeps everybody together'.

### 3.3 | Theme 3: Someone who understands

Participants in this study shared feelings regarding close connections with other parents of children with disabilities and also expressed challenges relating to others without a child with a disability. In the excerpt below, the participant describes her relationship with her P2P supporter as unique but also close, like family.

[I]t's nice to have somebody who's been there and walked the path before you .... Whereas it's nice to have your family who knows you and be able to talk to them, yet they have no idea what you're going through and the path that you're traveling. So every once in a while you find somebody who's both. (Participant 2)

Some participants talked about the sense of security provided to them by a P2P support parent who was available to talk, whereas another described their support parent as a positive role-model, someone who 'had done it and could show me that it's possible'.

Universally, participants reflected on challenges in relating to others. Participant 2 said that, 'even family members ... they really don't understand what another parent is going through'. When Participant 1 discussed challenges she faced talking to friends and family about her child following a developmental regression, she says, 'they're not necessarily going to be normal and not everybody knows what that's like'. Similarly, when recalling her thoughts at the time she reached out to P2P, Participant 4 says:

My husband doesn't understand, my parents don't understand, you know ... there's just something about talking to another mom who's going through it ... you can't find that everywhere.

These expressions of finding acceptance and understanding with another parent of a child with similar challenges highlight the unique kind of emotional support that P2P can provide through the careful matching of parents.

### 3.4 | Theme 4: Learning and sharing

The theme of learning and sharing encompassed parents' talk about setting goals and receiving training to help their child's health or development and to support other families. Some participants learned about opportunities to 'work on something' from their P2P support parent, whereas others developed plans to build capabilities on their own. Participant 2, who was new to the world of disability when she first took her daughter into foster care, recalled feeling isolated and not knowing what to do but described that a support parent 'can tell you about help that you can ask for that you might not be aware of'. She described further that these ideas of what she could do to help her child supported her in making treatment decisions and empowered her to advocate for her daughter.

Participant 5 shared that because her child's condition has evaded diagnosis, it was difficult to know the best services and treatments to support her development and that professionals provided her little clarity. Although her P2P support relationship did not work out due to a large age gap between children, she went on to found a support group for caregivers of children with disabilities that is now her 'passion'. She explains that her 'acts of service' to other families help her feel more in control and accepting of her daughter's disability. Participant 4 described her choice to become a P2P support parent saying, 'it comes full circle and it's equally as healing I think ... to try to help somebody else in this situation.'

### 3.5 | Theme 5: One size does not fit all

Although all of the parents interviewed for this study had contact with P2P support parents, their communication patterns varied in modes and intensity. Whereas some preferred text-based interactions, others wanted to speak with another parent by telephone or face to face. Most participants, however, used a mixture of communication types that was unique and matched their needs and preferences. When discussing her advocacy for a new P2P support match, Participant 3 shared that although she and her original support parent had a great deal in common, the support she received did not align with her preferences. '[W]e were trying to talk on email and I just felt like that wasn't the best fit for me. I really wanted to talk to someone on the phone.' Similarly, discussing her reason for contacting P2P, Participant 4 shared:

I did join ... Facebook groups for information but I just, I wasn't crazy about connecting that way and wanted a phone call. I wanted to be matched somehow ... instead of putting my life out there and saying, 'hey anybody else with 22Q kids struggling here?'

Participant 2 enjoyed the connection with her P2P support parent and also found benefits in 'getting referred to ... two or three Facebook groups'. Exchanging photos with their P2P match whether they were primarily communicating by phone or text/email was mentioned by most participants as an act that strengthened their bond and imparted positivity.

Another aspect of individual preferences related to the match itself. Participants mentioned aspects of their own or their child's identity as important to their support preferences when they recalled the intake process with a P2P programme coordinator. Participant 4 defined herself saying, 'I'm an older mom, so it was kind of a really big part of me, to work .... So, I wanted to talk to other moms that can show me that it is possible you can do this.' Whereas, Participant 3 discussed her reluctance to be matched with a parent who had a child with a similar diagnosis to her daughter's but was older because she did not want to 'have any pictures in my head about what could be'.

## 4 | DISCUSSION

The results of this study can be viewed through the lens of the FAAR Model (Patterson, 1988), as parents of young children with special health care needs are known to be challenged by increased demands associated with caring for their child and lack of knowledge and resources to meet their needs, which can hinder the family in adapting to the child's disability. Because P2P support parents are trained to provide information and emotional support, it is thought that P2P support reduces stress and supports the development of capabilities

in parents who receive a match when their child is newly diagnosed by providing access to disability knowledge, guidance in navigating systems of care, and sharing positive perceptions of their children and effective coping strategies through emotional support. Further, whether P2P support assists families of very young children in adapting to their child's disability and promotes family well-being was explored.

The themes and codes represented in this study are consistent with those found in a 2013 systematic review of peer support for parents of children with disabilities, which identified themes of shared social identity, learning from the experiences of others, personal growth and supporting others, and further found that although quantitative results have been inconsistent, qualitative studies overwhelmingly report that parents perceive benefits from peer support programmes (Shilling et al., 2013).

Because three of the five parents interviewed (Participants 3–5) were referred to P2P by a liaison embedded in the NICU, it is important to discuss the impact of the NICU experience on parents as well as research supporting the benefits of peer support for NICU parents. Recent studies indicate that parents of NICU babies are at high risk for post-traumatic stress disorder (PTSD) and that mothers may suffer the effects of PTSD more acutely than fathers (Aftyka et al., 2014). Similar PTSD prevalence rates are reported for parents of children with chronic illnesses or those requiring frequent surgeries (Cabizuca et al., 2009). Parents of premature babies who experience a traumatic birth and prolonged NICU stay may continue to experience PTSD symptoms for 2–3 years after bringing their baby home (Åhlund et al., 2009), likely impacting the parent–child relationship, child development and family functioning over an extended period. Research on P2P partnerships with NICU programmes over the past four decades indicates that peer support from another parent who has experienced the NICU firsthand enhances professional support and helps parents adjust to their child's condition, reducing stress and promoting caretaker efficacy (Levick et al., 2014). Additionally, P2P liaisons can improve family-centred care by providing support and education to both families and hospital staff (Pollock et al., 2020; Voos et al., 2015) and would likely provide benefits to a greater number of parents of young children diagnosed with special health care needs by being embedded within children's hospitals and developmental paediatric practices in addition to the NICU.

Although participants in this study described benefits to their own emotional state and improved access to information, indicating an increase in capabilities, they were hesitant to attribute improvements beyond themselves to P2P support. They did not perceive their P2P support experience as having an impact on their child or family unit, providing evidence that adaptation and family balance may not yet have been achieved. Further, participants indicated that they were often still managing 'day by day' showing that they may not be in a stable enough position relative to demands and capabilities to take a step back and evaluate their family functioning or make future plans. This finding is inconsistent with previous findings by Singer et al. (1999), who documented not only significant increases in acceptance of the child's disability in his quantitative evaluation of

four P2P programmes but also improved family closeness after 8 weeks of P2P support. This discrepancy may be due to differences in methodology or the age of the children (6.9 vs. 3.8 years), as parents and families of children with special health care needs may fare better once school-based supports and respite services are put in place due to a decrease in caregiving demands (Macdonald & Callery, 2008). Similarly, Bray and associates also reported increases for parents receiving peer support on a measure of health-related quality of life and family functioning, but their results did not reach significance (Bray et al., 2017). In accordance with previous findings, parents in this study reported feeling a desire to give back to other parents (Dodds & Singer, 2018) and found that providing support to others further reduced distress and isolation, building a larger social support circle (Bray et al., 2017).

Many parents of children with disabilities are introduced to the world of disability by medical professionals, who have their own jargon and scrutinize the bodies of children for abnormalities (Pearson et al., 2020). The juxtaposition of this experience of new parenthood with the expectation of a healthy pregnancy and birth can be stressful for parents and leave them fearful and without adequate resources, further putting them at risk for negative mental health sequelae (Minnes et al., 2015). Parents who are able to become a part of a peer community of others who have experienced similar challenges may be more likely to be able to restore balance in their homes and cope better (Shilling et al., 2013). Through the sharing of information and resources, parents who feel supported by a P2P relationship and have a positive peer model may be inclined to focus on actions to improve their child's progress and advocate for appropriate supports and services, building their sense of self-efficacy. However, in circumstances where parents who reached out to P2P felt that their preferences for specific match criteria were not followed or that communication modes were inadequate, parents were likely to request an additional match, create their own support groups and/or have continued challenges with stress and coping.

#### 4.1 | Limitations and future directions

This study had a small sample due to challenges recruiting families of young children during such a busy time of life. The sample included only White mothers and therefore results cannot be generalized to fathers, racially and ethnically diverse parents, non-parent caregivers and LGBTQ parents, who remain understudied in the family and disability literature, and may experience different combinations of stressors and resources. Additionally, parents from other cultures or who do not speak English may prefer group support meetings to a 1:1 match (Dodds et al., 2018), which are not offered by all P2P programmes. As this research targeted parents who had received a P2P match, parents of diverse backgrounds could have been inadvertently excluded. Additionally, qualitative research employing a retrospective design as well as longitudinal studies of parents of children with special health care needs who receive peer support should be conducted to better understand the path to adaptation and family

well-being across the lifespan. Future research should also explore whether the addition of known stress reducing practices such as mindfulness meditation (Singh et al., 2019) can augment P2P programmes, improving coping in parents of young children with disabilities or special health care needs and extending benefits beyond the parent to improvements in child development and family functioning.

## CONFLICT OF INTEREST

We have no known conflict of interest to disclose.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ORCID

Robin L. Dodds  <https://orcid.org/0000-0001-7748-0426>

Tanis J. Walch  <https://orcid.org/0000-0002-0557-7867>

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