
1-18-2023

Parental Contextual Factors and Decision-Making Related to Periviable Birth: An Integrative Review

Amy L. Wright

University of Toronto, amyl.wright@utoronto.ca

Elizabeth Mens

University of Toronto

Gausiha Rathitharan

University of Toronto

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>



Part of the [Critical Care Nursing Commons](#), [Maternal, Child Health and Neonatal Nursing Commons](#), and the [Pediatrics Commons](#)

Recommended APA Citation

Wright, A. L., Mens, E., & Rathitharan, G. (2023). Parental Contextual Factors and Decision-Making Related to Periviable Birth: An Integrative Review. *The Qualitative Report*, 28(1), 200-226. <https://doi.org/10.46743/2160-3715/2023.5565>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



Qualitative Research Graduate Certificate
Indulge in Culture
Exclusively Online • 18 Credits
LEARN MORE

NSU
NOVA SOUTHEASTERN
UNIVERSITY

NOVA SOUTHEASTERN

Parental Contextual Factors and Decision-Making Related to Periviable Birth: An Integrative Review

Abstract

Parents facing a periviable birth, or birth before 25 weeks of gestation, commonly engage in antenatal consultation with healthcare providers to determine a plan of care. Parents' pre-existing contextual factors, beliefs, and values influence their decisions regarding birth and the care of their infant. This study aims to understand the role of parental contextual factors and best-practices to their integration during antenatal consultation. The Whittemore and Knafl (2005) approach to conducting an integrative review along with thematic analysis was employed to determine and present the findings. Results describe three themes related to how contextual factors influence parental decision-making: personal values and hope, religion, and cultural and racial contexts. Parental contextual factors are important to integrate during antenatal consultation, yet how to do this is relatively understudied. A more thorough understanding will facilitate more individualized and effective counselling approaches for parents facing periviable birth.

Keywords

antenatal consultations, decision making, parents, periviable birth, preterm birth, integrative review

Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Parental Contextual Factors and Decision-Making Related to Periviable Birth: An Integrative Review

A.L. Wright, E. Mens, and G. Rathitharan

Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Canada

Parents facing a periviable birth, or birth before 25 weeks of gestation, commonly engage in antenatal consultation with healthcare providers to determine a plan of care. Parents' pre-existing contextual factors, beliefs, and values influence their decisions regarding birth and the care of their infant. This study aims to understand the role of parental contextual factors and best-practices to their integration during antenatal consultation. The Whittemore and Knafl (2005) approach to conducting an integrative review along with thematic analysis was employed to determine and present the findings. Results describe three themes related to how contextual factors influence parental decision-making: personal values and hope, religion, and cultural and racial contexts. Parental contextual factors are important to integrate during antenatal consultation, yet how to do this is relatively understudied. A more thorough understanding will facilitate more individualized and effective counselling approaches for parents facing periviable birth.

Keywords: antenatal consultations, decision making, parents, periviable birth, preterm birth, integrative review

Introduction

The preterm birth of an infant before 37 weeks of gestation is a life-altering event for a family. It is the leading cause of morbidity and mortality in children under five (Shah et al., 2018). In Canada, approximately 25,000-30,000 births each year are considered preterm, and a smaller portion of these are classified as extremely preterm, or periviable (22 - 25 weeks of gestation), which face the highest rates of morbidity and mortality (Lemyre & Moore, 2017; Shah et al., 2018). As a result, guidelines exist to assist healthcare providers in counselling families who are facing a periviable birth (PVB). This counselling, known as an antenatal consultation (ANC), is fraught with medical, ethical, moral, and social dilemmas and decisions.

Healthcare providers engage in ANCs with parents to determine a plan of care. Providers consider the best interests of the child and work towards informed consent with parents (Lemyre & Moore, 2017). Ideally, ANCs occur well before delivery, when the possibility of premature birth is identified, but at times they occur mere hours to moments before birth. The literature identifies various subjects to discuss within the consultations to better support parents' decision-making, including considerations for the timing of discussions, options for further follow up, types of professionals involved, preferred content, and tools to optimize information delivery (Daboval et al., 2016; Fish et al., 2021; Gaucher et al., 2016; Geurtzen et al., 2018; Grobman et al., 2010; Guillén et al., 2016, 2019; Kharrat et al., 2018; Tucker Edmonds, Hoffman, et al., 2019). While these suggestions are of benefit to parents, some studies show these communication strategies do not necessarily impact parents' choices (Haward et al., 2011; Pedrini et al., 2017). Instead, literature suggests that parents have pre-existing contextual factors, beliefs, and values which influence their decisions well before these conversations take place (Boss et al., 2008; Drago et al., 2018; Kavanaugh et al., 2005; Keenan

et al., 2005; Kidszun et al., 2020; McLemore et al., 2018; Moro et al., 2011; Tucker Edmonds et al., 2021; Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020; Tucker Edmonds, Savage, et al., 2019; Widding et al., 2019).

A recent integrative review of parental decision-making in the pediatric intensive care unit concluded that critical features impacting decision-making included: the nature of the relationship and communication between parents and healthcare providers, the parents' wish to be the ultimate decision makers for their child, and the parents' emotions, support systems, and the clinical status of their child (Wool et al., 2021). Researchers found that individual intrapersonal factors impacted decisions, identifying in particular hope, guilt, regret, and feeling overwhelmed. Additionally, environmental/contextual factors played a role: consideration for pain, discomfort or suffering of the child, and support systems available to the parents (Wool et al., 2021). Superdock et al. (2018) considered the ways in which religion and spirituality influence parents' decision-making and concluded that religion and spirituality may influence *how* decisions are made, rather than *what* decisions are made. The nebulous nature of the concepts of religion and spirituality lend themselves to diverse interpretation and meaning-making regarding decisions (Superdock et al., 2018). Blakeley et al. (2019) considered specifically life-limiting prenatal diagnoses and parents' decision-making through a meta-synthesis. Through a thematic synthesis of 22 papers, the authors identified several major influencing factors in parents' decision-making. These included the wish to do 'the right thing,' typically based on religious or moral beliefs, in addition to considering the child's future quality of life and parents' own pre-existing personal responsibilities and commitments. So, while parents typically firmly root their decision-making in the realities of suffering, pain, and comfort, their decisions are not made in a vacuum; contextual factors play a role.

It is important to situate ourselves as authors as our positionality motivates our research interests and influences our interpretations of data and ultimately the results of this review. First, we recognize our privileged positionality as academics and healthcare providers engaged in reproductive and perinatal healthcare within Canada. The first author is a neonatal nurse practitioner and assistant professor in a nursing faculty with European settler ancestry. Her program of research focuses on the needs of marginalized and racialized families and their experiences accessing health supports for their children. As such, in conjunction with her clinical expertise, she conceptualized and led the methodological approach to this review. The second author, also of European settler ancestry, is a non-binary, queer reproductive and perinatal health nurse. The third author is a public health nurse who specializes in applying best practice guidelines through knowledge translation strategies to optimize health outcomes. She identifies and connects strongly with her cultural background as a Sri Lankan woman. Finally, both first and second authors have recently become parents, motivating their interest in the topic based on their own experiences of receiving antenatal care.

The aim of this study was to review the literature to answer the question: how do parental contextual factors influence decision making during antenatal counselling for PVB? The results will support developing best-practices to integrating parental contextual factors during ANC.

Methods

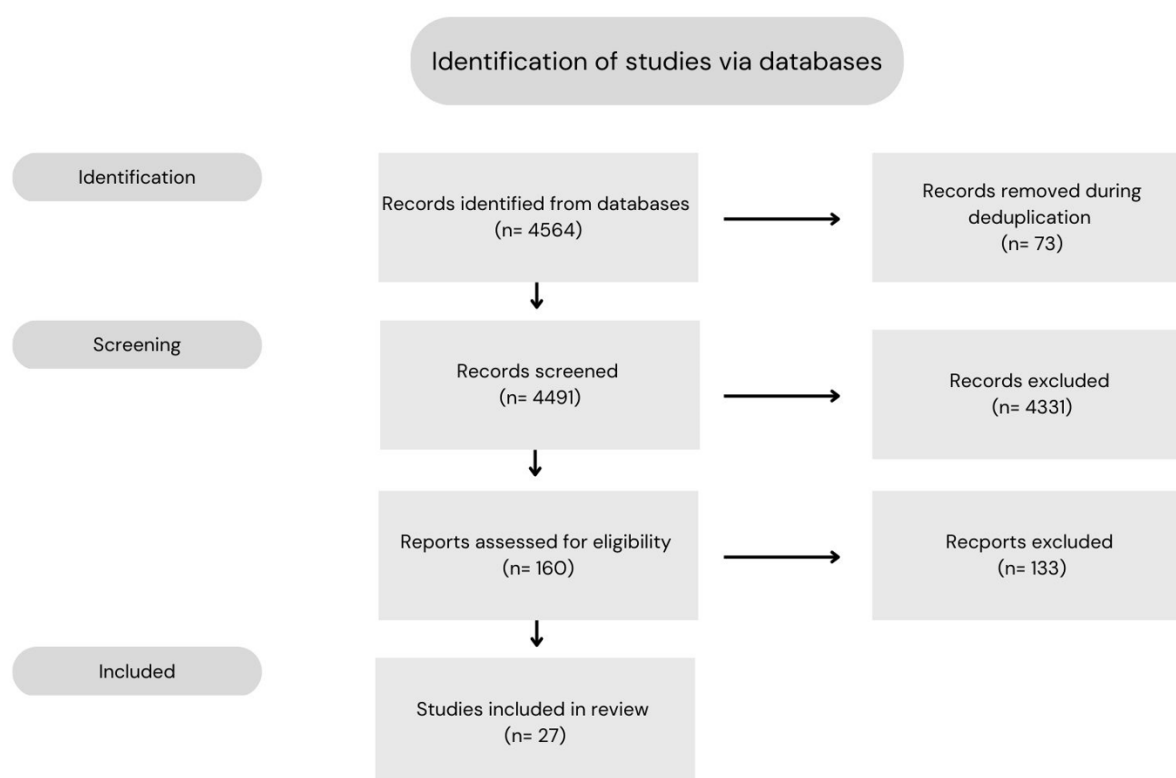
Literature Search

This integrative review uses the Whitemore and Knafl (2005) approach, which consists of five steps: (1) problem identification, (2) literature search, (3) quality evaluation, (4) data analysis, and (5) data synthesis. Integrative review methodology was chosen for its ability to thematically synthesize findings from both qualitative and quantitative studies. The goal is a

holistic understanding of the topic, and the methodology allows for patterns to be drawn from related areas of work. In the first step, problem identification, we have identified a limited understanding of how contextual factors influence parents' decision-making during ANC for PVB. In step two, a comprehensive search strategy was created in consultation with an information scientist (See Figure 1). Databases searched included Ovid-Medline, Ovid-EMBASE, Ovid-Psychinfo, Pubmed, CINAHL, Web of Science, Proquest, ERIC, and Google. Search terms included: "prenatal," "premature," "antenatal," "high-risk newborn," "Neonatal Intensive Care Units (NICUs)," "low birth weight," "infant," "periviability," "newborn resuscitation," "counsel," "prenatal consultation," and decision-making." Terms were developed in consultation with the information scientist. They were tested for their yield of articles, and those that had an impact on the yield were included. Based on the clinical expertise of authors one and two, terms were selected in addition to searching the keywords of relevant articles. Reference lists of included articles were mined for additional sources. Articles met inclusion criteria if they reflected the parents' experiences of antenatal counselling in regard to PVB and included mention of values, beliefs, or contextual factors. Other inclusion criteria were that papers must have been published after the year 2000 and be available in English.

Figure 1

PRISMA Chart. The Preferred Reporting Items for Systemic Reviews and Meta-Analyses (PRISMA) diagram demonstrates the flow of records through the screening process, from identification in databases to inclusion in the review (Page et al., 2021).



Data Evaluation of Quality

In step three, evaluation of quality, Joanna Briggs Institute (JBI) critical appraisal tools were used to critically evaluate the included empirical studies (Joanna Briggs Institute, n.d.) (See Tables 1-3). This quality appraisal tool addresses the credibility of the study, validity of

results, relevance, and contribution. Articles were included in the review regardless of quality; limitations of individual articles are addressed in the results.

Table 1

Critical Appraisal Checklist: Prevalence/Cross Sectional Studies

Question	Guillén et al., 2016	Haward et al., 2008	Kaempfer et al., 2009	Keehan et al., 2005	Edmonds et al., 2020	Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020
Was the sample frame appropriate to address the target population?	N	Y	Y	Y	Y	Y
Were study participants sampled in an appropriate way?	U	Y	Y	Y	Y	Y
Was the sample size adequate?	N	Y	Y	N	N	Y
Were the study subjects and the setting described in detail?	N	N	Y	Y	Y	Y
Was the data analysis conducted with sufficient coverage of the identified sample?	N	Y	Y	N	N	Y
Were valid methods used for the identification of the condition?	Y	Y	Y	Y	Y	Y
Was the condition measured in a standard, reliable way for all participants?	Y	Y	Y	Y	Y	Y
Was there appropriate statistical analysis?	Y	Y	Y	Y	Y	Y
Was the response rate adequate, and if not, was the low response rate managed appropriately?	U	Y	N/A	N	N/A	Y

Y=Yes, N=No, U=Unknown

Adapted from Joanna Briggs Institute

Table 2

Critical Appraisal Checklist: Randomized Controlled Trials

Question	Guillen et al., 2019	Kidszun et al., 2020	McDonnell et al., 2021
Was true randomization used for assignment of participants to treatment groups?	Y	Y	Y
Was allocation to treatment groups concealed?*	N	Y	Y
Were treatment groups similar at the baseline?	Y	Y	U
Were participants blind to treatment assignment?*	N	N	Y
Were those delivering treatment blind to treatment assignment?*	N	Y	N/A

Were treatment groups treated identically other than the intervention of interest?	Y	Y	Y
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y	Y	Y
Were participants analyzed in the groups to which they were randomized?	Y	Y	Y
Were outcomes measured in the same way for treatment groups?	Y	Y	Y
Were outcomes measured in a reliable way?	Y	Y	Y
Was appropriate statistical analysis used?	Y	Y	Y
Was trial design appropriate, and any deviations from the standard RCT design accounted for in the conduct and analysis of the trial?	Y	Y	Y

Y=Yes, N=No, U=Unknown

*In this checklist some “no’s” relate to whether a trial is blinded, and not to its lack of quality.

Adapted from Joanna Briggs Institute

Table 3
Critical Appraisal Checklist: Qualitative Studies

	B	D	D	E	G	J	K	K	M	M	P	T	T	T	T	T	U	W	Y	
	o	a	r	d	r	a	a	a	c	o	a	u	u	u	u	u	u	r	i	o
	s	b	a	w	o	g	v	v	L	r	y	c	c	c	c	c	i	d	u	
	s	o	g	a	b	e	a	a	e	o	o	k	k	k	k	k	n	d	n	
	et	v	o	r	m	r	n	n	m	et	t	e	e	e	e	e	&	i	g	
	al	al	et	d	a	et	a	a	o	al	et	r	r	r	r	r	S	n	et	
	.,	et	al	s	n	al	u	u	r	.,	al	E	E	E	E	E	y	g	al	
	2	al	.,	et	et	.,	g	g	e	2	.,	d	d	d	d	d	lt	et	.,	
	0	.,	2	al	al	2	h	h	et	0	2	m	m	m	m	m	e	al	2	
Qu	0	2	0	.,	.,	0	et	et	al	1	0	o	o	o	o	o	r	.,	0	
est	8	0	1	2	2	2	al	al	.,	1	0	n	n	n	n	n	n,	2	1	
io		1	8	0	0	0	.,	.,	2		7	d	d	d	d	d	2	0	2	
n		6		2	1		2	2	0			s,	s,	s,	s,	s	0	1		
				0	0		0	0	1			H	H	H	S	et	2	9		
							1	0	8			o	o	o	a	al	0			
							5	5				ff	ff	ff	v	.,				
												m	m	m	a	2				
												a	a	a	g	0				
												n,	n,	n,	e,	2				
												L	L	et	et	1				
												at	at	al	al					
												ia	ia	.,	.,					
												n	n	2	2					
												o,	o,	0	0					
												B	C	1	1					
												h	o	9	9					
												a	le							
												m	m							
												i	a							

re
co
ng
rui
ty
bet
we
en
the
res
ear
ch
me
th
od
ol
og
y
an
d
the
res
ear
ch
qu
est
io
n
or
ob
jec
tiv
es
?

Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y

Is the
re
co
ng
rui
ty
bet
we
en
the
res
ear
ch
me
th

od
ol
og
y
an
d
the
me
th
od
s
us
ed
to
col
lec
t
dat
a?
Is
the
re
co
ng
rui
ty
bet
we
en
the
res
ear
ch
me
th
od
ol
og
y
an
d
the
re
pr
es
ent
ati
on
an
d

N Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y

an
aly
sis
of
dat
a?

Is the re-
cog-
nui-
ty bet-
we-
en the
res-
ear-
ch me-
th-
od ol-
og-
y an-
d the
int-
er-
pr-
eta-
tio-
n of
res-
ult-
s?

Is the re-
a-
sta-
te-
me-
nt loc-
ati-
ng

Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y N

N Y N N N N Y Y Y N Y N N Y Y Y Y Y N

the
res
ear
ch
er
cul
tur
all
y
or
the
or
eti
cal
ly?

Y Y N Y Y Y Y Y Y Y Y N Y Y Y Y Y Y Y

Is
the
inf
lue
nc
e
of
the
res
ear
ch
er
on
the
res
ear
ch,
an
d
vic
e-
ve
rsa
,
ad
dr
ess
ed
?

Y Y Y Y Y Y Y Y Y Y Y Y N Y Y Y Y Y

Ar
e
pa
rti
cip
ant

s,
an
d
the
ir
vo
ice
s,
ad
eq
uat
ely
re
pr
es
ent
ed
?

Is the research ethical according to current criteria, for recent studies, and is the re

Y Y Y Y Y Y/N Y Y Y Y Y/N Y Y Y Y Y/N Y Y Y

ev
e
n
t
s,
an
d
is
the
re
vi

de
nc
e
of
eth
ica
l
ap
pr
ov
al
by
an
ap
pr
op
ria
te
bo
dy
?

Do Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y Y

the
co
ncl
usi
on
s
dr
aw
n
in
the
res
ear
ch
re
po
rt
flo
w
fro
m
the
an
aly
sis
,
or
int

er
pr
eta
tio
n,
of
the
dat
a?

Y=Yes, N=No, U=Unknown

Adapted from Joanna Briggs Institute

Data Extraction and Analysis

During step four, data describing parental contextual factors and their relevance to ANCs were extracted and analyzed using qualitative data analysis software NVIVO 12 Plus (QSR International, 2021). The data was coded using cyclical strategies developed by Saldaña (2016). The first cycle approach included structural and holistic coding to identify segments of the texts focused on contextual factors. Key search words such as “values,” “beliefs,” “god,” “religion,” “hope,” and “faith” were explored systematically. NVIVO’s search tool also identified synonyms of these words within the texts. Saldaña’s (2016) second coding cycle, directed at synthesizing themes and concepts, meshed with step five of the integrative review; the data is presented as a thematic summary in the results (Whittemore & Knafl, 2005).

Results

A total of 4,564 articles were retrieved from published database searches, and through hand searching relevant journals and reference lists. Following removal of duplicates, 4,491 articles were screened for relevance by title and abstract. 4,331 articles were irrelevant and excluded, and 160 articles were screened by full text. During full text review, articles were excluded because they (a) were published before the year 2000, (b) reflected only the healthcare provider’s experience, (c) solely related to preterm birth at later gestations (i.e., beyond 27 weeks), or (d) addressed the parents’ experiences solely as related to a neonatal death or fetal anomalies. Simulation-based studies, opinion pieces, review articles, and position statements from governing bodies were excluded. A total of 27 articles met our inclusion criteria, addressing decision-making and contextual factors directly (see Figure 1 for the screening process).

The studies included were primarily qualitative (n=18), but also included cross-sectional studies (n=5), randomized control trials (n=3) and one mixed methods study. They were assessed for quality using Joanna Briggs Institute (JBI) (n.d.) appraisal tools (see Tables 1-3). The mixed methods study was appraised using both the qualitative and cross sectional JBI tools to evaluate the quality of both methodologies. JBI critical appraisal tools were developed to help researchers assess trustworthiness, relevance, and results. Two studies (Young et al., 2012, Guillén et al., 2016) were determined to be of poor quality, as they were missing three or more criteria. Young et al. (2012) was assessed to be of poor quality due to a lack of congruity between its philosophical approach and research methodology. Guillén et al. (2016) was also of poor quality, lacking an appropriate sample size and failing to describe the sampling method and sample characteristics.

Contextual Factors According to Parents

Since the year 2000, an increasing number of articles have focused on the parents' experiences of and perspectives on periviable birth. For example, between the years 2000 to 2005, just five articles were found, whereas between the years 2016 to 2021, 33 articles were found. In the articles that address parents' decision-making when faced with a PVB, contextual factors were identified by parents as central to their decision-making (Boss et al., 2008; Grobman et al., 2010; Guillén et al., 2016, 2019; Jager et al., 2020; Kavanaugh et al., 2005, 2015; Keenan et al., 2005; Kidszun et al., 2020; Moro et al., 2011; Payot et al., 2007; Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020; Young et al., 2012). Three themes were identified related to parental contextual factors central to parents' decision-making: (1) personal values and hope, (2) religion, and (3) cultural and racial contexts. These will each be described in depth (see Table 4 for excerpts from the literature that substantiate each theme).

Table 4

Contextual factors in relation to decision making

Personal Values

Mothers were asked open-ended questions about what they considered when deciding how their infant would be treated to delineate further their responses. Most mothers responded with personal values, beliefs, or experiences, rather than mentioning the medical information that was presented during their counseling. (Keenan et al., 2005, p. 107)

All that is to say that, in the end, [medical] advances can't just come down to technology. There is the human dimension, which should always be integrated. (Payot et al., 2007, p. 1494)

Hope

Two mothers mentioned hope with regard to decision-making and the infant's survival. In one case, hope that the infant would survive fueled the mother's determination to make physicians try and save the infant in the delivery room. While this mother thought there was less than a 1% chance that her daughter would live, she indicated that she had hope until the last moment. (Moro et al., 2011, p. 54)

Parents indicated that they wanted honest information but also wanted to hold onto some ray of hope because that is what helps parents to get through devastating times. Mothers knew stories of infants who survived extreme prematurity. (Kavanaugh et al., 2005, p. 357)

I mean they were great doctors and nurses but I really can't remember what was discussed because I was scared. I knew she was going to pass away but I still had a glimmer of hope. I'm sure they did discuss genetic things but I was in the mindset where I didn't want to hear that because everything is going to be okay. (Boss et al., 2008, p. 585)

Share everything...not just all of the gloomy stuff because you can imagine how a mother would feel (when she is) 23 weeks and (her) bag of waters breaks. (Grobman et al., 2010, p. 907)

Religion

When they told me they thought she was not going to survive, I put it in God's hands. God had made her into a baby, and if I had made it that far [with the pregnancy], it was up to Him. (Boss et al., 2008, p. 585)

You know everyone told me don't worry about what [the doctors] say, she will make it, she's a miracle. And so that's pretty much all I heard. (Boss et al., 2008, p. 585)

There was a lady who said, 'You know this child has all of these problems, why are you going to bring him into the world? Are you looking for God to step in?' I said, 'Well, as a matter of fact, I am.' If you think God is going to come in and perform a miracle, you have a right to do that. (Boss et al., 2008, p. 585)

They said cerebral palsy...blindness or deafness. You know, stuff like that. I did not really feed into that though. Like I said, God got the last word. (Tucker Edmonds, Savage, et al., 2019, p. 823)

Culture

Well many times I did have to use my English, and I just felt better using the interpreter so that I could understand better. (Drago et al., 2018, p. 953)

I had my family's support, her father's support, and his family's support. *Sample statement, aligning with researchers' identified Latino cultural norm 'familismo'* (Drago et al., 2018, p. 957)

Racism & Racial Context

... I've watched the same doctor. He was nice to this little white couple, but a single black woman coming in, even though the father came with me, it was like I did feel like the treatment was different. And it's like I do feel like if we don't have private insurance they do treat us differently. They cut costs, cut edges, or don't tell us everything at some of these hospitals. (McLemore et al., 2018, p. 130)

Like I said, for some people it would be different, but for me, you know, I feel like my baby is a strong baby and I feel like she would be able to tough it out, you know?—Pregnant woman 2, non-white (African American) (Tucker Edmonds et al., 2021, p. 399)

Personal Values & Hope

Personal values and hope were identified by study participants as integral to their decision-making process (Boss et al., 2008; Daboval et al., 2016; Drago et al., 2018; Grobman et al., 2010; Guillén et al., 2016, 2019; Jager et al., 2020; Kavanaugh et al., 2005, 2015; Keenan et al., 2005; Moro et al., 2011; Payot et al., 2007; Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020; Tysdahl et al., 2019; see Table 4 for excerpts from the literature that substantiate this theme). Boss et al. (2008), Keenan et al. (2005), and Moro et al. (2011) delved into the reasoning behind parents' decisions. Parents explained why doctors' predictions related to neonatal mortality and morbidity were not the main factors in their decision-making. Often, parents believed in the possibility of a good outcome, regardless of which statistics were presented. In a study of 30 parents facing PVB, when parents chose resuscitation, the theme of hope was pervasive in their reasoning. (Jager et al., 2020). These findings were echoed in Kavanaugh et al.'s (2005) work, wherein "parents indicated that they wanted honest information but also wanted to hold onto some ray of hope because that is what helps parents to get through devastating times. Mothers knew stories of infants who survived extreme

prematurity” (p. 357). Similarly, Drago et al. (2018) and Daboval et al. (2016) found that parents wished for factual information framed in a hopeful or more optimistic light.

A recent case study emphasized the contrast in framing neonatal outcomes between the healthcare providers at two different hospitals and how hope played a role (Tysdahl et al., 2019). Two couples facing preterm delivery around 23 weeks of gestation were given varying prognoses and outcomes based on the capacity of the hospital they were in. Upon transfer to a higher-level hospital, both couples remarked on the ability of the healthcare providers at the new hospital to provide honest morbidity and mortality information in a more compassionate way. The transfer to a new hospital and change in healthcare providers allowed the couples to regain hope. Both couples elected to resuscitate their infants, “giving them a chance at life,” aware their children would have to defy the odds to survive (Tysdahl et al., 2019, p. 2).

Factors which led to parents basing their decisions on hope rather than prognostic data were difficulty understanding the information presented, feeling overwhelmed, or being in the midst of their own medical crises (Boss et al., 2008). During decision-making, differences in perspective on treatment approach sometimes led to conflict or disengagement between parents and the healthcare team (Daboval et al., 2016; Drago et al., 2018; Grobman et al., 2010; Payot et al., 2007). Healthcare providers can take a more hopeful and compassionate approach to their delivery of ANC to better relate to parents and their needs during a time of crisis. Using plain language and avoiding jargon can support parents in understanding information about birth and prognosis and better support their ability to make decisions.

Religion

Religion and faith were identified by parents as integral to their decision-making (Boss et al., 2008; Grobman et al., 2010; Guillén et al., 2016; Haward et al., 2008; McDonnell et al., 2021; Tucker Edmonds, Savage et al., 2019, Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020; see Table 4 for quotes from the literature that illustrate this theme). Tucker Edmonds, Savage, et al. (2019) found that for parents who held religious beliefs, their faith played an important role in how they made decisions. Similarly, in Boss et al. (2008), 25 participants were interviewed between ten months and five years after the death of their child. Half of the participants had been diagnosed with fetal anomalies and half with preterm labour. Many parents sought advice and were advised by family or friends to “trust in God” and “pray for miracles” (Boss et al., 2008, p. 585). Some felt that while life or death would be determined by God, physicians should do everything possible to preserve the life of their child.

Guillén et al. (2016) gathered input from parents on the creation of an information tool regarding PVB. Parents identified important themes they wished covered by the tool, including religion (Guillén et al., 2016). In a study focused on message-framing and perinatal resuscitation decisions, Haward et al. (2008) found a significant relationship between the degree of religiousness and the choices of parents: those who self-identified as highly religious indicated they strongly valued the preservation of life. They found this association held true regardless of whether prognosis was framed positively (as survival and non-disability) or negatively (as mortality and disability). Less religious participants in this study were more affected by the framing of the prognosis. A similar study, conducted with 839 child-bearing age women, presented a hypothetical scenario of labour at 22 weeks of gestation and considered the ordering of information on survival and disability (McDonnell et al., 2021). Researchers found both non-organizational religiosity (i.e., prayer) and beliefs in the sanctity of life, were associated with the choice of intensive rather than comfort care (McDonnell et al., 2021). Keeping in mind that these are hypothetical studies, parents’ preferences may prove different if placed in a real-world situation.

Parents interviewed by Grobman et al. (2010) noted that physicians infrequently discussed factors parents used to make decisions – including religious beliefs and financial circumstances – and instead focused on death and disability. Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al.'s (2020) work on values clarification noted that personal mental and physical health, as well as financial concerns, were ranked just as highly as religion by birthing parents as having an impact on decision-making. Notably, researchers found that religion played a much less important role for the support person of the birthing person (Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020). Instead, support persons were more focused on practical concerns such as finances and careers.

Religion was an important contextual factor influencing parental decision-making for those facing PVB. Faith, trust in a God, miracles, and the preservation of life were affiliated concepts amongst those with religious beliefs and were found to influence decision-making regardless of infant prognosis or how information was conveyed to parents.

Cultural and Racial Context

Cultural and racial context are also key factors which determine how individuals access and navigate the healthcare system (see Table 4 for excerpts from the literature that illustrate this theme). Racialized parents faced unique barriers to care due to not speaking English or receiving racist and discriminatory care (Drago et al., 2018; Edwards et al., 2020; Kaempf et al., 2009; McLemore et al., 2018; Tucker Edmonds et al., 2021; Widding et al., 2019). For example, Drago et al. (2018), found that Spanish-speaking patients may feel limited in their opportunities to communicate due to the availability of translators, and that they did not have the same opportunities to ask questions as their English counterparts. Similarly, McLemore et al. (2018) found that women of colour at risk for PVB experienced the healthcare system to be stressful and disrespectful. Participants reported racism and discrimination mediated their access to healthcare services prenatally, information received intrapartum, and follow-up in the NICU. Men of colour interviewed by Edwards et al. (2020) in a study of male partners' experiences had unmet informational needs, compounding their mistrust of the healthcare system and hindering their ability to contribute to decision-making.

Cultural resources, such as social norms and ideals related to childbirth and family life also mediated parents' experiences of PVB (Kaempf et al., 2009; Widding et al., 2019). Culture colours the lens through which parents view the world; in particular, their roles and responsibilities as spouses, as parents, and their perceptions of life and death, including the importance they place on quality of life (Kaempf et al., 2009). Indeed, culture has been noted to influence decision-making in a multitude of ways, necessitating an individualized approach to ANC by healthcare providers. For example, non-White women were found to be largely optimistic during antenatal consultation for PVB, focused on overcoming pain and suffering, and tending to see their unborn children as resilient and exceptional (Tucker Edmonds et al., 2021). Their concerns centered around survival, and most could not recall any discussions with their doctors about pain, suffering, or comfort. Faith was a strong driver in decision-making for non-White parents and some parents denied disability as a possible outcome or avoided the topic entirely. Conversely, the authors found White women to be more *realistic* about their infant's prognosis, and shared beliefs that raising a child with disability would be difficult and be challenging for their own mental health (Tucker Edmonds et al., 2021). Therefore, if healthcare providers explore cultural resources with families, they may cultivate a more constructive understanding of a parents' experience of PVB (Widding et al., 2019). All studies emphasized that an individually-tailored approach to counselling through actively listening to parents' experiences, beliefs, and preferences will improve racialized parents' experiences of

ANC (Drago et al., 2018; Edwards et al., 2020; Kaempf et al., 2009; McLemore et al., 2018; Tucker Edmonds et al., 2021; Widding et al., 2019).

Integrating Contextual Factors in Shared Decision-Making

Shared decision-making (SDM) allows for the presentation of medical facts, risks, and benefits and the exploration of a patient's values and preferences with the goal being consensus between provider and patient regarding the plan of care (Klassa et al., 2016). In PVB, much variation has been found in decision-making, ranging from parents preferring to make their own decisions entirely, to parents preferring that a physician make the decision regarding care (Daboval et al., 2016). One notable study from Norway suggested that the healthcare provider "balance out the instinct of saving" and ensure that the responsibility for choosing life or death not rest solely in parents' hands (Ursin & Syltern, 2020). Several parents suggested strict guidelines for resuscitation, taking the decision out of the healthcare provider's and parents' hands entirely. The authors conclude that the appropriate involvement of each family will be dependent on cultural and personal factors, and that through SDM, eliciting these can assist with determining what is right for each family (Ursin & Syltern, 2020).

In interviews debriefing ANCs with parents facing PVB, Daboval et al. (2016) discovered that parents valued physicians who were able to build trustworthy relationships with them in which their concerns were welcomed and heard. Parents appreciated physicians who offered time to think, provided balanced information, and offered choices. Even when physicians' and parents' opinions differed on treatment plans, so long as all options were respectfully presented, parents welcomed the information. In cases where parents' values and concerns regarding resuscitation were elicited before presenting the medical facts, parents were more satisfied with their decision-making experiences and had more trust in their physicians.

In more recent years, work has been done to identify the values parents hold and help healthcare teams apply them within a SDM model (Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al., 2020; Tucker Edmonds, Hoffman, Laitano, Coleman-Phox, et al., 2020; Tucker Edmonds, Savage, et al., 2019). Tucker Edmonds, Hoffman et al. (2019) conducted focus groups of parents and healthcare providers who had experience with PVB to design a decision-support tool aimed at facilitating conversation and understanding. Participants supported a tablet application and felt the inclusion of family testimonial videos was important. In another study, Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al. (2020) developed exercises for families to use to help clarify their values and assist them in navigating decisions around PVB, particularly regarding death, disability, and quality of life. Most who participated in the study found the activities helpful, and none found them harmful. As a result of this study, the authors developed the Perivable GOALS decision aid. The aid incorporates outcomes data, values clarification exercises, and videos of parents who experienced a PVB. Approximately 95% of parents found the content of the decision aid to be *just right* and researchers found it helpful in engaging parents in SDM (Tucker Edmonds, Hoffman, Laitano, Coleman-Phox, et al., 2020, p. 1290).

Understanding parents' values, beliefs, and preferences is essential to engaging in SDM yet determining these prior to ANC can be challenging. Tools and technology as suggested by Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al. (2020) might be helpful strategies to allow healthcare providers to better understand the contextual factors influencing parents' decision-making. It may better equip providers to incorporate these factors into an individualized approach to ANC.

Conflict with the Healthcare Team

PVB is fraught with morally ambiguous and difficult circumstances; SDM can assist with navigating these. However, several researchers noted the difficulties encountered when parents felt healthcare providers were not attending to their concerns (Daboval et al., 2016; Drago et al., 2018; Grobman et al., 2010; Payot et al., 2007). Daboval et al. (2016) noted that when parents felt their values were not respected, they disengaged from the SDM process. This disengagement could occur because of the style or content of the physician's consultation. Grobman et al. (2010) found that while both providers and patients agreed that support and information were key to successful ANCs, their actual recommendations were less homogenous. Clients preferred a more individualized, hopeful approach, while physicians prized an objective one and were wary of optimistic framing (Grobman et al., 2010). Drago et al. (2018) noted when parents perceived physicians as too negative, it affected the doctor-patient relationship, causing breakdown. In a study where healthcare providers made specific recommendations, and they did not fit with parents' expectations and needs, parents felt abandoned and isolated (Payot et al., 2007). To summarize, an individualized approach that is both respectful of parents' values and beliefs and hopeful might promote better SDM between providers and parents facing PVB.

Challenges

Various researchers noted challenges parents encountered during decision-making (Boss et al., 2008; Daboval et al., 2016; Drago et al., 2018; Grobman et al., 2010). First: often, parents were experiencing their own medical emergencies. Similarly, Drago et al. (2018) found that maternal health emergencies were a limiting factor in parents' ability to comprehend and process their ANCs. A lack of prior experience with PVB also negatively impacted their processing ability (Drago et al., 2018; Grobman et al., 2010). In addition, time from admission to decision might be limited, and there may be no pre-existing relationship between patient and physician (Boss et al., 2008). The lack of patient-provider relationship led to significant communication difficulties, with parents unable to disclose their values or concerns due to time constraints or lack of opportunity.

As discussed previously, the communication skills of the healthcare providers had a significant impact on the parents' engagement in and understanding of the ANC. Parents noted that the use of jargon hindered their ability to comprehend their healthcare providers (Grobman et al., 2010). Drago et al. (2018) identified intercultural communication challenges, including language barriers, that had a significant impact. When providers and patients were not able to connect, parents disengaged from the process (Daboval et al., 2016; Drago et al., 2018). Left with the sense that their values and preferences were not part of the healthcare team's process, parents felt powerless. Tools such as those described by Tucker Edmonds, Hoffman, Laitano, Coleman-Phox, et al. (2020) might offer realistic solutions for healthcare providers who seek to better understand parents' values and beliefs in order to offer more individualized and collaborative approaches to ANC and SDM.

Discussion

This integrative review summarizes what is known about the contextual factors that impact parents' decision-making when faced with PVB. It explored the literature which provides insight into the current approach to integrating these contextual factors into ANCs, and challenges to doing so. Developing an understanding of these factors, and of their

integration into an individualized and SDM approach to ANCs is essential for healthcare providers providing support to parents facing PVB.

Understanding and integrating the more ambiguous aspects of parents' decision-making, such as personal values, hope and religion, is a challenge well recognized in pediatric literature (Superdock et al., 2018). These factors predate the challenges parents face in the healthcare system but are not routinely assessed by healthcare providers or multidisciplinary teams (Grobman et al., 2010; Superdock et al., 2018). However, when the values and concerns of parents are explored *before* presenting medical prognoses, parents report improved satisfaction with their ANCs (Daboval et al., 2016). If these values are not explored by the healthcare team, it may limit the ability to provide individualized counselling and inhibit a deeper understanding of parents' decisions, thereby creating or furthering the rift between parents and healthcare providers. This not only negatively affects parents' experiences and trust of the healthcare system, but can also become a cause for moral and ethical distress for healthcare providers. ANCs often occur at the very outset of the relationship between parents and healthcare providers; thus it behooves providers to start the relationship off well by building a respectful and trusting relationship in which individualized care and SDM can occur. This is not only in the best interests of the infant and family unit, but also the healthcare team, who will continue to care for the family going forward in the best ways they can. Race and culture are complex factors which mediate healthcare access and experiences. Periviable births are more common among families of colour than White families (Kirby, 2016), as are associated complications (Janevic et al., 2019). Furthermore, research suggests that healthcare providers' approaches to SDM with parents are influenced by both race and culture (Derrington et al., 2018). Racism and cultural incongruence are identified as factors negatively affecting communication and relationships between birthing people and their healthcare providers; how these factors influence SDM during ANC must be specifically addressed in any future research led by or working collaboratively with people of colour. In addition, health policy should be made to dictate that all healthcare providers engage in education related to equity, diversity, and inclusion to learn how to practice culturally-effective care regardless of a patient's ethnicity, as has been called for by the American Academy of Pediatrics (Mullett et al., 2022) and the UN declaration on the rights of Indigenous Peoples (United Nations Educational Scientific and Cultural Organization (UNESCO), 2017). Parents whose primary language differs from the dominant language are at a disadvantage in navigating the healthcare system. Studies have reported barriers to health literacy experienced by immigrants, including a reduced likelihood of asking questions or for clarification, misunderstanding medical treatments, and the inability to express their wishes to healthcare providers due to lack of translation services (Bajgain et al., 2020). This can be disempowering and lead to poor health outcomes (Bajgain et al., 2020). It is all the more essential in diverse communities that parental contextual factors, including faith, culture, and racism, are considered and respected during ANCs. This will help to ensure we work towards cultural safety in our ANC; that is: "engage in ongoing self-reflection and self-awareness and hold [our]selves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity" (Curtis et al., 2019, p. 187). In turn, individualized and family-focused care will assist to reduce some of the parental stressors and anxiety related to PVB and admission of infants to neonatal care units, and help move the healthcare team and family towards a SDM approach.

For many years, decision-making regarding periviable birth rested with the physician or medical authority figure. However, in 2002, the American Association of Pediatrics revised their clinical recommendations, advocating for joint decision-making between neonatologists and parents and advising parental wishes to be respected (Bastek et al., 2005). Over the next two decades, a shift towards parental involvement and SDM is clear (Alderson et al., 2006;

Barker et al., 2019; Daboval et al., 2016; Griswold & Fanaroff, 2010; Kaempf et al., 2009; Klassa et al., 2016; Ladd & Mercurio, 2003; Lemyre & Moore, 2017; Payot et al., 2007; Stokes et al., 2014). Boss et al. (2012) considered how to teach physicians the skills required to balance their treatment preferences and ethical obligations with parental autonomy. In other hospitals, programs were developed to help healthcare providers better understand the patient experience of high-risk pregnancy and birth and become better counsellors as a result (Klassa et al., 2016). Much of the literature notes a balance, endeavouring to engage parents in decision-making to the extent with which they are comfortable, providing recommendations or moving to a more directive style should parents wish (Daboval et al., 2016; Geurtzen et al., 2018; Ursin & Syltern, 2020). In one small recent study, parents reported a high level of SDM in relation to PVB; their later decisional conflict and regret scores were low, indicating that this communication strategy may be effective in mediating challenging decisions (Geurtzen et al., 2021). Shared decision-making has become the idealized standard of care for patients facing PVB.

Nevertheless, while SDM is the ideal, barriers were identified to its use in ANCs. These mimic the more generalized NICU literature, where significant challenges to the implementation of SDM have been noted (Parish et al., 2021). In counselling in both NICU and pediatric settings, barriers include lack of appropriately tailored information, time, skill, power imbalances, the emotional state of patients and families, practice/cultural norms (such as the expectation for the healthcare provider to direct care), and the absence of continuity of care (Boland et al., 2019; Parish et al., 2021). Boland et al. (2019) noted that healthcare providers have difficulty knowing when and how to elicit parents' values, and how to integrate them into ANCs. Tucker Edmonds, Hoffman, Laitano, Bhamidipalli, et al. (2020) and Daboval et al. (2016) provide some insight here: their research indicates values should be assessed before recommendations are made and the use of tools and decision aids can be useful. Due to the unpredictable nature and sometimes rapid progression of PVB, we must consider the provision of information and SDM in the immediate and later postnatal periods, when parents may be asked to provide resuscitation directives to healthcare providers.

Limitations

This review surveyed the last two decades of literature regarding ANCs and tracks a period of notable change, both in medical advancements in the resuscitation of early gestation infants, and of counselling approaches for families facing medical decisions. This review focused solely on the decision-making of parents and did not consider the perspectives of healthcare providers. It also includes several studies in which the definition of extreme preterm included slightly older gestations of 26-27 weeks or was not specified. Furthermore, the experience of racism is culturally and historically mediated, and so, the varying locations and makeup of healthcare teams may affect the experiences of people of colour within the system. Geographic differences also mean differences in medical costs for parents, and while this factor was only briefly explored, it may weigh heavily into parents' decisions in some areas but not in others. For example, understanding the factors influencing the decision-making of Indigenous people, immigrants, and refugees in Canada, as well as the impact of socialized medicine (no cost to parents) on SDM during ANC are important contextual details unique to the Canadian healthcare landscape. Similarly, inquiries that investigate the perspectives of parents in other unique contexts would be worthwhile.

Future Research

Further research is required to understand how the contextual factors identified in this review influence parental decision-making and how parents want these factors integrated into ANCs. Only one study described a well-received tool to determine parental values and beliefs (Tucker Edmonds, Hoffman, Laitano, Coleman-Phox, et al., 2020). More research is needed to understand how best to elicit these contextual details in effective and timely ways to integrate them into emergency ANCs for PVBs. Additional gaps in the literature include a lack of research addressing gender diversity, as all birthing parents were identified as women and all studies included primarily heterosexual partners. Only one study examined the male partner's experience specifically, but not in relation to decision-making. The role of partners in decision-making is essential to understand, along with further consideration for the perspectives of gender and sexually diverse individuals and partners. Certainly, gender is an important contextual factor influencing decision-making that has just barely been explored. It is also clear that cultural differences and racism affect parents' decision-making and thus also play a role in ANCs. A better understanding of the impact of these factors is necessary to determine whether commonalities exist across cultures and races that might be incorporated into medical decision-making tools and assessments to effectively elicit this information in a timely way. Furthermore, a paucity of data surrounding race and PVB exists. Future research as suggested above – the factors influencing the decision making of Indigenous people, immigrants and refugees in Canada, and the role of socialized medicine on SDM during ANC, as well as the needs of gender and sexually-diverse parents – would help fill important gaps in understanding within the Canadian literature.

Conclusion

Families faced with PVB are challenged to make decisions regarding resuscitation amidst social, moral, ethical, and physical concerns. From the literature, contextual factors impacting parents' decision-making include personal values and hope, religion, culture, and racism. To navigate these conversations between healthcare providers and parents, in integrating these contextual factors, SDM is the model identified in the literature as most appropriate. To date, there are no publicly available evidence-based tools designed for healthcare providers assessing parents' values related to PVB. Further, high quality, region-specific qualitative research is required to understand which contextual factors influence medical decision-making about PVB and how best to integrate these factors into ANCs. With a deeper understanding of the contextual factors at play in parents' decision-making and tools to integrate those factors in ways parents prefer, healthcare providers will be better placed to serve families and improve communication, aligning ever more closely with the SDM model.

References

- Alderson, P., Hawthorne, J., & Killen, M. (2006). Parents' experiences of sharing neonatal information and decisions: Consent, cost and risk. *Social Science & Medicine*, 62(6), 1319-1329. <https://doi.org/10.1016/j.socscimed.2005.07.035>
- Bajgain, B. B., Bajgain, K. T., Badal, S., Aghajafari, F., Jackson, J., & Santana, M.-J. (2020). Patient-reported experiences in accessing primary healthcare among immigrant population in Canada: A rapid literature review. *International Journal of Environmental Research and Public Health*, 17(23), 8724. <https://doi.org/10.3390/ijerph17238724>
- Barker, C., Dunn, S., Moore, G. P., Reszel, J., Lemyre, B., & Daboval, T. (2019). Shared

- decision making during antenatal counselling for anticipated extremely preterm birth. *Paediatrics & Child Health*, 24(4), 240-249. <https://doi.org/10.1093/pch/pxy158>
- Bastek, T. K., Richardson, D. K., Zupancic, J. A. F., & Burns, J. P. (2005). Prenatal consultation practices at the border of viability: A regional survey. *Pediatrics*, 116(2), 407-413. <https://doi.org/10.1542/peds.2004-1427>
- Blakeley, C., Smith, D. M., Johnstone, E. D., & Wittkowski, A. (2019). Parental decision-making following a prenatal diagnosis that is lethal, life-limiting, or has long term implications for the future child and family: A meta-synthesis of qualitative literature. *BMC Medical Ethics*, 20(1), 56. <https://doi.org/10.1186/s12910-019-0393-7>
- Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. *Implementation Science*, 14(1), 7. <https://doi.org/10.1186/s13012-018-0851-5>
- Boss, R. D., Donohue, P. K., Roter, D. L., Larson, S. M., & Arnold, R. M. (2012). “This is a decision you have to make”: Using simulation to study prenatal counseling. *Simulation in Healthcare*, 7(4), 207–212. <https://doi.org/10.1097/SIH.0b013e318256666a>
- Boss, R. D., Hutton, N., Sulpar, L. J., West, A. M., & Donohue, P. K. (2008). Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. *Pediatrics*, 122(3), 583-589. <https://doi.org/10.1542/peds.2007-1972>
- Curtis, E., Jones, R., Tipene-Leach, D., Walker, C., Loring, B., Paine, S.-J., & Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health*, 18(1), 174. <https://doi.org/10.1186/s12939-019-1082-3>
- Daboval, T., Shidler, S., & Thomas, D. (2016). Shared decision making at the limit of viability: A blueprint for physician action. *PLoS ONE*, 11(11), e0166151. <https://doi.org/10.1371/journal.pone.0166151>
- Derrington, S. F., Paquette, E., & Johnson, K. A. (2018). Cross-cultural interactions and shared decision-making. *Pediatrics*, 142(Supplement 3), S187-S192. <https://doi.org/10.1542/peds.2018-0516J>
- Drago, M. J., Guillén, U., Schiaratura, M., Batza, J., Zygmunt, A., Mowes, A., Munson, D., Lorenz, J. M., Farkouh-Karoleski, C., & Kirpalani, H. (2018). Constructing a culturally informed Spanish decision-aid to counsel Latino parents facing imminent extreme premature delivery. *Maternal and Child Health Journal*, 22(7), 950–957. <https://doi.org/10.1007/s10995-018-2471-8>
- Edwards, B. N., McLemore, M. R., Baltzell, K., Hodgkin, A., Nunez, O., & Franck, L. S. (2020). What about the men? Perinatal experiences of men of color whose partners were at risk for preterm birth, a qualitative study. *BMC Pregnancy and Childbirth*, 20(1), 91. <https://doi.org/10.1186/s12884-020-2785-6>
- Fish, R., Weber, A., Crowley, M., March, M., Thompson, C., & Voos, K. (2021). Early antenatal counseling in the outpatient setting for high-risk pregnancies: a randomized control trial. *Journal of Perinatology*, 41, 1595-1604. <https://doi.org/10.1038/s41372-021-00933-x>
- Gaucher, N., Nadeau, S., Barbier, A., Janvier, A., & Payot, A. (2016). Personalized antenatal consultations for preterm labor: Responding to mothers’ expectations. *The Journal of Pediatrics*, 178, 130-134.e7. <https://doi.org/10.1016/j.jpeds>
- Geurtzen, R., Draaisma, J., Hermens, R., Scheepers, H., Woiski, M., van Heijst, A., & Hogeveen, M. (2018). Various experiences and preferences of Dutch parents in prenatal counseling in extreme prematurity. *Patient Education and Counseling*, 101(12), 2179–2185. <https://doi.org/10.1016/j.pec.2018.07.003>
- Geurtzen, R., van den Heuvel, J. F. M., Huisman, J. J., Lutke Holzik, E. M., Bekker, M. N., &

- Hogeveen, M. (2021). Decision-making in imminent extreme premature births: Perceived shared decision-making, parental decisional conflict and decision regret. *Journal of Perinatology*, 41(9), 2201-2207. <https://doi.org/10.1038/s41372-021-01159-7>
- Griswold, K. J., & Fanaroff, J. M. (2010). An evidence-based overview of prenatal consultation with a focus on infants born at the limits of viability. *Pediatrics*, 125(4), e931-e937. <https://doi.org/10.1542/peds.2009-1473>
- Grobman, W. A., Kavanaugh, K., Moro, T., Deregner, R. A., & Savage, T. (2010). Providing advice to parents for women at acutely high risk of periviable delivery. *Obstetrics and Gynecology*, 115(5), 904–909. <https://doi.org/10.1097/AOG.0b013e3181da93a7>
- Guillén, Ú., Suh, S., Wang, E., Stickelman, V., & Kirpalani, H. (2016). Development of a video decision aid to inform parents on potential outcomes of extreme prematurity. *Journal of Perinatology*, 36(11), 939–943. <https://doi.org/10.1038/jp.2016.127>
- Guillén, Ú., Mackley, A., Laventhal, N., Kukora, S., Christ, L., Derrick, M., Batza, J., Ghavam, S., & Kirpalani, H. (2019). Evaluating the use of a decision aid for parents facing extremely premature delivery: A randomized trial. *Journal of Pediatrics*, 209, 52-60.e1. <https://doi.org/10.1016/j.jpeds.2019.02.023>
- Haward, M. F., Kirshenbaum, N. W., & Campbell, D. E. (2011). Care at the edge of viability: Medical and ethical issues. *Clinics in Perinatology*, 38(3), 471–492. <https://doi.org/10.1016/j.clp.2011.06.004>
- Haward, M. F., Murphy, R. O., & Lorenz, J. M. (2008). Message framing and perinatal decisions. *Pediatrics*, 122(1), 109–118. <https://doi.org/10.1542/peds.2007-0620>
- Jager, S., Kavanaugh, K., Hoffman, S., Laitano, T., Jeffries, E., & Tucker Edmonds, B. (2020). Parents' descriptions of neonatal palliation as a treatment option prior to periviable delivery. *Journal of Perinatal & Neonatal Nursing*, 34(2), 178-185. <https://doi.org/10.1097/JPN.0000000000000483>
- Janevic, T., Zeitlin, J., Auger, N., Egorova, N. N., Hebert, P., Balbierz, A., & Howell, E. A. (2019). Association of race/ethnicity with very preterm neonatal morbidities. *Obstetrical & Gynecological Survey*, 74(4). <https://doi.org/10.1097/OGX.0000000000000667>
- Joanna Briggs Institute. (n.d.). *Critical appraisal tools*. Retrieved March 31, 2021, from <https://jbi.global/critical-appraisal-tools>
- Kaempf, J. W., Tomlinson, M. W., Campbell, B., Ferguson, L., & Stewart, V. T. (2009). Counseling pregnant women who may deliver extremely premature infants: Medical care guidelines, family choices, and neonatal outcomes. *Pediatrics*, 123(6), 1509–1515. <https://doi.org/10.1542/peds.2008-2215>
- Kavanaugh, K., Roscigno, C. I., Swanson, K. M., Savage, T. A., Kimura, R. E., & Kilpatrick, S. J. (2015). Perinatal palliative care: Parent perceptions of caring in interactions surrounding counseling for risk of delivering an extremely premature infant. *Palliative and Supportive Care*, 13(2), 145–155. <https://doi.org/10.1017/S1478951513000874>
- Kavanaugh, K., Savage, T., Kilpatrick, S., Kimura, R., & Hershberger, P. (2005). Life support decisions for extremely premature infants: Report of a pilot study. *Journal of Pediatric Nursing*, 20(5), 347–359. <https://doi.org/10.1016/j.pedn.2005.03.006>
- Keenan, H. T., Doron, M. W., & Seyda, B. A. (2005). Comparison of mothers' and counselors' perceptions of predelivery counseling for extremely premature infants. *Pediatrics*, 116(1), 104–111. <https://doi.org/10.1542/peds.2004-1340>
- Kharrat, A., Moore, G. P., Beckett, S., Nicholls, S. G., Sampson, M., & Daboval, T. (2018). Antenatal consultations at extreme prematurity: A systematic review of parent communication needs. *Journal of Pediatrics*, 196, 109-115.e7. <https://doi.org/10.1016/j.jpeds.2017.10.067>

- Kidszun, A., Matheisl, D., Tippmann, S., Inthorn, J., Mahmoudpour, S. H., Paul, N. W., & Mildenerger, E. (2020). Effect of neonatal outcome estimates on decision-making preferences of mothers facing preterm birth: A randomized clinical trial. *JAMA Pediatrics*, *174*(7), 721–722. <https://doi.org/10.1001/jamapediatrics.2020.0235>
- Kirby, R. S. (2016). Race and preterm birth rates in North America. *Canadian Medical Association Journal*, *188*(1), 13-14. <https://doi.org/10.1503/cmaj.151160>
- Klassa, P. J., Dendrinis, S., Penn, A., & Radke, J. (2016). Shared decision making: Through the patient's eyes. *Journal of Perinatal and Neonatal Nursing*, *30*(3), 228–232. <https://doi.org/10.1097/JPN.000000000000192>
- Ladd, R. E., & Mercurio, M. R. (2003). Deciding for neonates: Whose authority, whose interests? *Seminars in Perinatology*, *27*(6), 488–494. <https://doi.org/10.1053/j.semperi.2003.10.008>
- Lemyre, B., & Moore, G. (2017). Counselling and management for anticipated extremely preterm birth. *Paediatrics and Child Health (Canada)*, *22*(6), 334–350. <https://doi.org/10.1093/pch/pxx058>
- McDonnell, S., Yan, K., Kim, U. O., Flynn, K. E., Liegl, M. N., Leuthner, S. R., McIntosh, J. J., & Basir, M. A. (2021). Information order for periviable counseling: Does it make a difference? *The Journal of Pediatrics*, *235*, 100-106.e1. <https://doi.org/10.1016/j.jpeds.2021.03.058>
- McLemore, M. R., Altman, M. R., Cooper, N., Williams, S., Rand, L., & Franck, L. (2018). Health care experiences of pregnant, birthing and postnatal women of color at risk for preterm birth. *Social Science and Medicine*, *201*, 127–135. <https://doi.org/10.1016/j.socscimed.2018.02.013>
- Moro, T. T., Kavanaugh, K., Savage, T. A., Reyes, M. R., Kimura, R. E., & Bhat, R. (2011). Parent decision making for life support for extremely premature infants: From the prenatal through end-of-life period. *Journal of Perinatal and Neonatal Nursing*, *25*(1), 52–60. <https://doi.org/10.1097/JPN.0b013e31820377e5>
- Mullett, T. A., Rooholamini, S. N., Gilliam, C., McPhillips, H., Mollie Grow, H. (2022). Description of a novel curriculum on equity, diversity and inclusion for pediatric residents. *Journal of the National Medical Association*, *113*(6), 616-625. <https://doi.org/10.1016/j.jnma.2021.05.014>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S.,...Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372*(n71), 1-9. <https://doi.org/10.1136/bmj.n71>
- Parish, O., Williams, D., Odd, D., & Joseph-Williams, N. (2021). Barriers and facilitators to shared decision-making in neonatal medicine: A systematic review and thematic synthesis of parental perceptions. *Patient Education and Counseling*, *105*(5), 1101-1114. <https://doi.org/10.1016/j.pec.2021.08.033>
- Payot, A., Gendron, S., Lefebvre, F., & Doucet, H. (2007). Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision? *Social Science and Medicine*, *64*(7), 1487–1500. <https://doi.org/10.1016/j.socscimed.2006.11.016>
- Pedrini, L., Prefumo, F., Frusca, T., & Ghilardi, A. (2017). Counselling about the risk of preterm delivery: A systematic review. *BioMed Research International*, *2017*(7320583). <https://doi.org/10.1155/2017/7320583>
- QSR International. (2021). *NVIVO 12 plus*. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home/>
- Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). SAGE.

- Shah, P. S., McDonald, S. D., Barrett, J., Synnes, A., Robson, K., Foster, J., Pasquier, J.-C., Joseph, K. S., Piedboeuf, B., Lacaze-Masmonteil, T., O'Brien, K., Shivananda, S., Chaillet, N., & Pechlivanoglou, P. (2018). The Canadian preterm birth network: A study protocol for improving outcomes for preterm infants and their families. *CMAJ Open*, *6*(1), E44-E49. <https://doi.org/10.9778/cmajo.20170128>
- Stokes, T. A., Watson, K. L., & Boss, R. D. (2014). Teaching antenatal counseling skills to neonatal providers. *Seminars in Perinatology*, *38*(1), 47–51. <https://doi.org/10.1053/j.semperi.2013.07.008>
- Superdock, A. K., Barfield, R. C., Brandon, D. H., & Docherty, S. L. (2018). Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: A qualitative study. *BMC Palliative Care*, *17*(1), 107. <https://doi.org/10.1186/s12904-018-0360-y>
- Tucker Edmonds, B., Hoffman, S. M., Laitano, T., Bhamidipalli, S. S., Jeffries, E., Fadel, W., & Kavanaugh, K. (2020). Values clarification: Eliciting the values that inform and influence parents' treatment decisions for periviable birth. *Paediatric and Perinatal Epidemiology*, *34*(5), 556–564. <https://doi.org/10.1111/ppe.12590>
- Tucker Edmonds, B., Hoffman, S. M., Laitano, T., Coleman-Phox, K., Castillo, E., & Kuppermann, M. (2020). User-testing of a decision-support tool for parents facing threatened periviable delivery: The Periviable GOALS decision aid. *Patient Education and Counseling*, *104*(6), 1286-1294. <https://doi.org/10.1016/j.pec.2020.10.004>
- Tucker Edmonds, B., Hoffman, S. M., Laitano, T., Jeffries, E., Jager, S., & Kavanaugh, K. (2021). Diverse perspectives on death, disability, and quality of life: An exploratory study of racial differences in periviable decision-making. *Journal of Perinatology*, *41*(3), 396–403. <https://doi.org/10.1038/s41372-020-0739-5>
- Tucker Edmonds, B., Hoffman, S. M., Lynch, D., Jeffries, E., Jenkins, K., Wiehe, S., Bauer, N., & Kuppermann, M. (2019). Creation of a decision support tool for expectant parents facing threatened periviable delivery: Application of a user-centered design approach. *Patient*, *12*(3), 327–337. <https://doi.org/10.1007/s40271-018-0348-y>
- Tucker Edmonds, B., Savage, T. A., Kimura, R. E., Kilpatrick, S. J., Kuppermann, M., Grobman, W., & Kavanaugh, K. (2019). Prospective parents' perspectives on antenatal decision making for the anticipated birth of a periviable infant. *Journal of Maternal-Fetal and Neonatal Medicine*, *32*(5), 820–825. <https://doi.org/10.1080/14767058.2017.1393066>
- Tysdahl, C., Tysdahl, T., Wendt, J., Wendt, L., & Feltman, D. M. (2019). Helping families navigate center variability in antenatal counseling for extremely early births. *Pediatrics*, *144*(5), e20191625. <https://doi.org/10.1542/peds.2019-1625>
- United Nations Educational Scientific and Cultural Organization (UNESCO). (2017). Indigenous Peoples: UN declaration on the rights of Indigenous Peoples (UNDRIP) related to education and intergenerational transmission. Available online <http://www.unesco.org/new/en/indigenous-peoples/education-and-intergenerational-transmission/undrip-ed/>
- Ursin, L., & Syltern, J. (2020). Protect us from ourselves: Balancing the parental instinct of saving. *Nursing Ethics*, *27*(5), 1282-1296. <https://doi.org/10.1177/0969733019871691>
- Whittemore, R., & Knaf, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546-553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Widding, U., Hägglöf, B., & Farooqi, A. (2019). Parents of preterm children narrate constructive aspects of their experiences. *Journal of Clinical Nursing*, *28*(21–22), 4110–4118. <https://doi.org/10.1111/jocn.14948>
- Wool, J., Irving, S. Y., Meghani, S. H., & Ulrich, C. M. (2021). Parental decision-making in

- the pediatric intensive care unit: An integrative review. *Journal of Family Nursing*, 27(2), 154-167. <https://doi.org/10.1177/1074840720975869>
- Young, E., Tsai, E., & O’Riordan, A. (2012). A qualitative study of predelivery counselling for extreme prematurity. *Paediatrics & Child Health*, 17(8), 432-436. <https://doi.org/10.1093/pch/17.8.432>

Author Note

A.L. Wright, PhD, Nurse Practitioner, is an Assistant Professor at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. Dr. Wright conceptualized the manuscript, and was primarily responsible for protocol development, data analysis and writing the manuscript. Corresponding author: amyl.wright@utoronto.ca

E. Mens, BA (Hons.), BScN, RN, MI is a nurse and research assistant at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Ms Mens contributed to developing the protocol, participated in data analysis and writing the manuscript.

G. Rathitharan, BSc, MSc, BScN, RN is a nurse and research assistant at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Ms Rathitharan contributed to developing the protocol, search strategy, participated in data analysis and writing the manuscript.

Copyright 2023: A.L. Wright, E. Mens, G. Rathitharan and Nova Southeastern University.

Article Citation

- Wright, A.L., Mens, E., & Rathitharan, G. (2023). Parental contextual factors and decision-making related to periviable birth: An integrative review. *The Qualitative Report*, 28(2), 200-226. <https://doi.org/10.46743/2160-3715/2023.5565>
-