EVIDENCE BASED MIDWIFERY

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EVIDENCE BASED MIDWIFERY

CONTENTS

Hello *Watson*

Back in the 1990s, I went to London to be trained by Professor Dave Sacket to learn how to use evidence-based medicine to improve clinical decision-making and enhance my clinical midwifery care. It was the new approach to facilitating 'judicious clinical decision-making' based on best evidence from critically appraised topics, warmly referred to as 'CATs'.

However, the limitations of the application in practice quickly became apparent as although the concept was admirable, the infrastructure to support it was not developed. There was a distinct need for better quality research to be undertaken to answer clinical questions. The research needed to be focused on answering questions that were raised by practitioners and that were relevant to everyday clinical decision-making.

In addition, access to more sophisticated search engines to retrieve appropriate published research evidence became a priority once the research had been undertaken. Getting the research evidence published remains a key challenge. The speed of the information retrieval was dependent on the power of the computer to search and retrieve information. The hardware had to change and mobile access was a natural trajectory. In addition, only the evidence that was digital was easy to access and the digitalisation of books and papers became a priority. The movement is now part of our medical and midwifery history and the key principles have been embedded into the decision-making faculties of every healthcare practitioner. The seeds for this journal, *Evidence Based Midwifery,* came from that awareness of the value of publishing research findings and having papers that were easily accessible and of high quality.

Open-access to research has become a major factor for healthcare workers as new research floods our practice at a phenomenal rate and impacts decision-making. Knowing the data and having access to multiple sources – such as pharmacology, biological data, outcomes from clinical trials, guidelines, adverse reports, evaluation data and, more recently, public perception and evaluation data – makes our decision-making more complex but, the more access we have to data, the more evidence-informed that decision-making can be.

Evidence Based Midwifery has become an open-access resource and this huge innovation means that anyone across the globe with access to the internet can find published research papers courtesy of the Royal College of Midwives. This is a mega-resource that needs to be recognised and valued, not only for REF2021, but for midwifery education, practice and research.

In the space of 25 years, microfiche and hard copies of journals bound and logged for access by people on two feet have gone forever. The days of searching reference books while physically standing in the library are history. However, a trip down memory lane is valuable. Looking back, we embraced the new technology with its power to bring us closer to the evidence from our work machines. We were delighted with the rapidity of the advances and as the technology permeated our spaces and made access quicker, we forgot the old ways and kept looking for more innovation; more databases and more help with synthesising the evidence. But as the volume increases, our ability to interpret it slows down our decision-making. Home access, mobile access, faster downloads and high-speed broadband are now the accepted norm. Laboratories and patient records cannot keep up with our demands for instant access to data and that is where we are likely to see major change in the next few years as the world moves to accept and expect immediate access to confidential patient data.

Say we want access to our personal records; our data might be held in the form of a smart card available for rapid access with our fingerprint or eye scan. We will control who shares our personal file and it is only a matter of time before these changes become reality. Today, for example, I opened an app called HiVision and was amazed to see the information it provided when I took a photo of my TV. Of course, the app is designed to encourage me to make purchases and when I looked at the screen I saw data on the TV type, cost and places to buy. The principle here is the intelligence of the machine and its capacity to provide data. In this example, the data was of no interest, but the potential for the technology to be applied to medical cases such as Type 1 diabetes or pregnancy is mind-blowing. Indeed, one of my current PhD students is working in this field and the array of intelligent sensor technologies for self-screening is growing rapidly (Adams et al, 2019).

We only need to remember how quickly we adopted high-speed access to data and this is evidenced in how quickly film-rental shops went out of fashion as people turned to Sky Movies and then Netflix and Amazon Prime. The market for videos and DVDs has almost dried up as our homes become a central IT hub that will soon show us our laboratory test results, appointments and online health checks and offer us mental health and wellbeing digital support chats.

The occularcentric power of the technology to show us everything within the three-click principle is alluring, captivating and maybe even mesmerising. Social media and internet addiction (Huang, 2017) is a modern disease and Mallorqui Bague et al (2017) report co-morbidities where gambling is linked to behavioural disorders such as 'problematic internet use and gaming disorders'. However, some may argue that technology per se is not the culprit as it cannot operate without the human touch. I see this as a debate for another day and we will consider this in another editorial.

The invisibility of the technology needs to be noted and we need to be aware of it. We only notice the technology when it does not work, not when it is offering us more and more power to illuminate what we cannot see with our normal vision. It's a small but important point. When we want to access the electronic patient record (EPR) to enter a visit to the day obstetrical unit and find there is no access because the module does not exist on our patient information system, we are irritated and complain bitterly. We expect the technology will fix the problem and in most cases it does. When we learned

how to access the library remotely through our mobile phones and home computers our tedious journeys to the library were over and our physical exercise levels dropped.

Enter the FitBit and we have a technologically designed motivator that encourages us to get up and walk. It can even notify us of our lack of movement. The sensor power is amazing and we seem to be continually in the process of developing new technologies that solve one problem while simultaneously giving us another. We proceed to develop a solution to the new problem and a new one emerges and so the cycle is propagated. The journey has been rapid and our young midwives will see even more rapid changes in the power of technology now that we have a new super computer, *Watson*, which is artificial intelligence at its peak. Developments in this field are set to change the world of healthcare, as we know it, with great stealth and powerful social media advertising.

I smile at my children and grandchildren when they call Dr Google, who has an answer for everything. Now, I can foresee a future where Dr Watson will be our first port of call on our clinical iPads and our computer linked screens at the bedside of every woman in our care. We will open our smartphones and retrieve data from the lab and from the EPR and child health system in seconds not minutes. Our smart phones will be ultra powerful and Big Brother watching every move will become the norm. The multiple data sets that I have personally tried to find technical solutions to combine (CTG, IVAC, dinomapp, urinometer, epidural etc.) will be brought together in seconds and data will be integrated and interpreted and decisions proposed for acceptance or rejection.

So let me introduce you to Dr Google's competitor, Dr Watson. IBM designed *Watson*, a super fast computer, in 2011 to take questions and provide answers. It does this by taking the question and analysing it as input, producing a set of features and hypotheses by rapidly processing data it has consumed as 'content' before searching for the best answer (Howard, 2014). It is cognitively programmed and was originally designed to take on the best game players in the US on the *Jeopardy!* quiz show (Rutter and Jennings) and it won the top prize of $1 million (see http://bit.ly/EBM_Jeopardy). For a detailed description of how *Watson* searches millions of information sources in seconds and analyses them to come up with an answer, visit http://bit.ly/EBM_Watson.

The potential for *Watson* to be applied to healthcare is huge and the past eight years have witnessed a growing body of evidence that demonstrate its applicability to a wide variety of healthcare areas, including screening, diagnostics, treatments and evaluation outcomes.

IBM created *IBM Watson Health* to help researchers and healthcare providers enhance their evidence-based (not just informed) clinical decision-making and provide key facts about their research profiles across the world (see http://bit.ly/Watson_Health). IBM makes a clear statement with reference to the major problems with data overload and the expectation of medical data to double every 73 days by 2020. It also estimates that each one of us will 'generate enough data to fill 300 million books' (IBM Facts, 2019). IBM makes a strong case for the increasing time spent by each one of us in clinical practice

interacting with the electronic patient record (approximately 70% of our time) and propose Watson Health as a resource for the provision of individualised patient care plans and, in our case, this is woman-centred, evidence-based care.

This technology is now being tested. When I look at current technology, the advances are phenomenal and it is only a matter of time before we will be using such systems just as comfortably as we now use our mobile phone to access our emails, Twitter accounts and Facebook updates. This new computer can make sense of structured and unstructured data, use natural languages and it has the power to analyse multiple data sets.

It's a mind-blowing thought that a computer is cognitively programmed to think like a human being and can learn from tasks undertaken. This system has been through several stages of morphing and testing in a variety of healthcare settings.

Today, we are reading about the future evidence-based midwifery care supported by artificial intelligence. But it won't belong until *Watson*, or a system like it, will search, collate, interrogate, hypothesise and propose decisions for our consideration based on mega-data crunching. This is the future reality of our health care delivery. Evidence-informed care will be replaced by the evidence-based care. Evidence based on mega-data that has been filtered, cleaned and appropriated for our consideration.

I will end on a key point – we are still in command of this data as we initiate the action and we are the people who act on the evidence. The power is in our hands and the machine is still our artificial assistant.

Professor Marlene Sinclair (editor)

PhD, MEd, PGDip/ED, BSc, RM.

Professor of midwifery research and head of the Centre for Maternal, Fetal and Infant Research at Ulster University, Northern Ireland

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Measuring the silence: development and initial psychometric testing of the Stillbirth-stigma scale

Danielle Pollock[1] Hons, Professor Adrian Esterman[2] Phd, Dr Elissa Pearson[3] Phd, Dr Megan Cooper[4] RM, Phd, Associate Professor Tahereh Ziaian[5] Phd, Associate Professor Jane Warland[6] Phd.

1. University of South Australia, School of Nursing and Midwifery. Email: danielle.pollock@unisa.edu.au
2. University of South Australia, School of Nursing and Midwifery / Australian Institute of Health and Tropical Medicine, James Cook University. Email: adrian.esterman@unisa.edu.au
3. University of South Australia, School of Psychology, Social Work and Social Policy. Email: elissa.pearson@unisa.edu.au
4. University of South Australia, School of Nursing and Midwifery. Email: megan.cooper@unisa.edu.au
5. University of South Australia, School of Psychology, Social Work and Social Policy. Email: tahereh.ziaian@unisa.edu.au
6. University of South Australia, School of Nursing and Midwifery. Email: jane.warland@unisa.edu.au
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Abstract

Background: The World Health Organization (WHO), and the *Lancet's* 2011 and 2016 Stillbirth Series, all released a call to action to reduce stillbirth stigma by 2020. However, there is meagre research regarding the concept of stigma as it relates to those who have experienced a stillbirth. Furthermore, there is currently no tool to measure and define the extent and types of stigma felt by bereaved parents; thus, there is no way to determine if stillbirth stigma is being reduced. Therefore, this study sought to create a stillbirth-stigma scale to measure the extent and type of stigma experienced by bereaved parents to gain a better understanding of its constructs. It is anticipated that this scale can be used as a tool to measure any changes in stillbirth stigma to assess if it is being reduced.

Methods: Items for the initial administration of the stillbirth-stigma scale were developed by adapting existing validated stigma scales, gathering information from existing literature, and consulting end-users. Eighty-three potential scale items were piloted on 100 Australian bereaved parents (94 mothers; six fathers) through an online survey.

Ethics: This study was approved on 5 December 2016 by the University of South Australia Human Research Ethics Committee, protocol number 0000036017.

Results: An exploratory factor analysis identified four factors (perceived devaluation stigma, discrimination, disclosure and self-stigma), with the final structure having good factor structure, internal consistency (a=.77), and reliability (r=.90).

Conclusion: The stillbirth-stigma scale has the potential to measure the extent and type of stigma experienced by bereaved parents. Future assessment needs to be conducted to further validate the scale.

Keywords: Scale-development; stigma; stillbirth; perinatal health; methodology; measurement; psychology; health; midwifery; obstetrics; evidence-based midwifery

Introduction

Stillbirth is a prominent health issue worldwide. The World Health Organization's (WHO) definition of stillbirth is baby born with no signs of life from 28 weeks' gestation and/or a gestational weight of one kilogram (Blencowe et al, 2016). According to this definition, it is estimated that globally more than 2.6 million stillbirths occur each year, which equates to more than 7,000 stillbirths per day (Blencowe et al, 2016). While low income countries shoulder 98% of the burden, Australia was ranked 11th in the world in 2016 with a stillbirth rate of 2.7/1,000 births (Flenady et al, 2016).

The psychological and social consequences of stillbirth have been well explored in literature (Burden et al, 2016; Heazell et al, 2016; Ogwulu et al, 2015; Brierley-Jones et al, 2015; Haws et al, 2010; Kiguli et al, 2015; Trulsson and Rådestad, 2004). Bereaved parents have higher rates of depression, anxiety, post-traumatic stress disorder (PTSD) and financial hardship than those who have not had a stillbirth; and these issues often last for years (Burden et al, 2016; Heazell et al, 2016). The silent and taboo nature of stillbirth has led some researchers to state that there is a stigma associated with those who have lost a child as a stillbirth. The need to address stigma was reiterated in the 2011 and 2016 *Lancet* series dedicated to understanding stillbirth. They contained a call to action for the identification of mechanisms to reduce stillbirth stigma (Horton and Samarasekera, 2016; Goldenberg et al, 2011; Scott, 2011).

Stigma is a complex and multifaceted concept that is not clearly defined in the literature (Deacon et al, 2005). Goffman (1968) proposed that stigma devalues a person's worth within society; this devaluation occurs by attacking (whether consciously or unconsciously) parts of or their whole personal identity (Goffman, 1968). Link and Phelan (2001) developed the work of Goffman (1968), theorising that stigma occurs when an individual is separated, labelled, stereotyped, discriminated against and/or experiences a loss of status due to their condition. Link and Phelan (2001) proposed that people are stigmatised for three reasons: to keep people down (for example, people in higher social classes may have a vested interest in dominating another group); keeping people 'in' (the following of specific social rules to benefit the continued functioning of society); and to keep people 'away' (avoidance of disease). Furthermore, stigmatisation can only occur in the context of a power imbalance, where the stigmatised are not able to challenge the stigmatisers (Link and Phelan, 2014; Link and Phelan, 2001).

Several types of stigma, for example perceived self (internalised) and public stigma, have been identified within

the broader literature with each having different outcomes and associated interventions (Sheehan et al, 2016). However, stigma cannot be addressed unless it is first identified and tools that offer the ability to recognise stigma are essential. Thus, stigma scales can provide insight into which type of stigma is having an impact upon the stigmatised. Currently, many stigma scales have been developed and applied to areas such as mental health (King et al, 2007), gambling (Donaldson et al, 2015) and HIV/Aids (Phillips et al, 2011). Several constructs that assist in describing the stigma experiences have been identified in the development of existing stigma scales. These constructs include perceived devaluation, discrimination, disclosure, and even the positive aspects of stigmatisation (Brohan et al, 2010). The extensive work in the conceptualisation and measurement achieved in other areas (mental health, HIV, gambling) cannot be applied to the stillbirth experience without adaptation. To date, there has been no validated stigma scale, nor a conceptual framework, for understanding the experiences of those who have had a stillbirth.

Research that directly explores stillbirth stigma is limited. However, a plethora of studies, mostly qualitative in nature, have discussed potential consequences from stigmatisation after stillbirth. Murphy's (2012) study of mostly mothers in the UK was not directly exploring stigma as it related to stillbirth; however, she did reveal the stigmatising effects of stillbirth (i.e. changing relationships and attitudes of others), without the participants directly mentioning stigma. They also experienced social isolation and acts of avoidance, with some participants stating that people would cross the road to avoid them. Brierley-Jones et al (2015) also reported that stigma was present after stillbirth through the mother's (negative) experience of showing or discussing their stillborn baby's mementos to others. She suggested that it negatively affected the way mothers and fathers created and shared memories of their child.

Froen et al (2011) conducted an international survey measuring the perception of stillbirth across 135 countries with 2,731 responses from both health professionals and parents. Participants perceived their stillbirth to be a taboo subject and therefore they experienced stigma (Froen et al, 2011). This group also reported that the discussion of stillbirth or any acknowledgement of their child was silenced, with four in five women believing that their community expected them to forget their stillborn child and have another.

Although the broader literature highlighted above suggests that stigma exists in stillbirth, it falls short of explicitly measuring the extent or the type of stigma associated with stillbirth. Therefore, the prevalence and type of stillbirth stigma experienced by bereaved parents are still not yet known or understood. Measurement and discernment of types of stigma experienced by bereaved parents who have endured a stillbirth is a necessary first step in developing appropriate strategies and interventions to reduce stigma and therefore assist those who are bereaved by a stillbirth. Thus, in this paper, we report the development and initial psychometric evaluation of a stillbirth-stigma scale.

Methods

Scale development
Several stigma scales, which had strong validity and reliability, as well as stillbirth literature, were accessed to broadly capture the experience of stigma:
1) A scoping review of literature related to stillbirth and stigma (Pollock et al, 2019);
2) Utilising the lived experiences of the researchers on the team (D Pollock, C Foord, J Warland);
3) Consultation with end-user organisation (Still Aware);
4) Adapting items in existing stigma scales to the stillbirth context (Donaldson et al, 2015, King et al, 2007, Phillips et al, 2011).

a) The mental health stigma scale (King et al, 2007)
The mental health stigma scale contains 28 items and has strong internal consistency (a=.87). The scale includes three subscales that measure: discrimination (a=.87), disclosure (a=.85) and potential positive aspects of mental health issues (a=.64). The scale has been tested on a variety of participants with differing diagnoses, age, gender and ethnicities. All questions were adapted from this scale to make them more relevant to the stillbirth experience. For example, instead of stating 'the general population is understanding of my mental illness,' this statement was changed to 'the general population is understanding of my stillbirth.'

b) The perceived devaluation/discrimination scale (Link, 1987)
Perceived stigma is the perception of shame and the fear of discrimination as perceived by the stigmatised individual (Rafael et al, 2010). This scale is one of the most popular psychometric tools utilised in stigma research; the scale has 12 items and two sub-scales: perceived devaluation (six items) and discrimination (six items) and has strong internal consistency (a=.87). The scale has been validated across a range of situations and demographics (Brohan et al, 2010). All items within the perceived devaluation/discrimination scale were adapted for this study. For example, we adapted the statement 'most people would willingly accept a former mental patient as a close friend,' to 'most people would accept a person who has had a stillbirth as a close friend.'

c) The internalised stigma scale (Phillips et al, 2011)
Internalised or self-stigma occurs when the individual becomes aware of the negative stereotypes, subsequently agreeing with them, and applying them to their situation (Corrigan et al, 2010). The scale is a single factor and has strong internal consistency (a=.91 to a=.92). All 10 items on the internalised stigma scale were adapted from the version used to measure stigma in the HIV/Aids population. For example, instead of 'having HIV infection is like being branded with shame,' this statement was changed to 'having had a stillbirth is like being branded with shame.'

Once an initial list of items had been created, the scale was sent to an end-user organisation (Still Aware) and two mothers who had experienced a stillbirth (neither of whom were connected to the research team) for review to determine face validity. After review, 83 items had been developed, identified and adapted for the initial scale.

Procedures

To be included in the survey to inform the development of the scale, the participants must have experienced a stillbirth in Australia, be currently residing in Australia, be over the age of 18, and their most recent stillbirth not considered a medical termination. The survey was administered online through Survey Monkey (surveymonkey.com) and participants were informed it might take up to an hour to complete. Data from the completed surveys was then imported directly into SPSS (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp).

To enable test-retest, participants who had completed the survey, were invited to complete a portion of the survey (psychometric scales) again. Participants who agreed to complete the test-retest left their personal email address and a personal code, which would then be used to identify and match the participants with their responses. Researcher (DP) contacted the participants via email, five to seven days after they had completed the survey, and provided them with a link to complete the validation survey.

Recruitment

Recruitment for this study occurred in February 2017 through various Australian pregnancy-loss support organisations (such as, Bears of Hope, Still Aware and SIDS and Kids SA). After seeking approval from the owners and administration of the websites, a post including the details and link to the study was placed on their Facebook pages. The study was presented in the post as a general survey on the experiences of parents, bereaved by a stillbirth. To avoid any pre-conceived bias, there was no mention that this study was measuring stigma in the advertising, information page, or in any questions before the participants undertook the 83-item survey.

Ethical considerations

This study was approved on 5 December 2016 by the University of South Australia Human Research Ethics Committee, protocol number 0000036017. Before starting the online survey, all participants were informed through an information sheet that they would be asked about their experiences related to stillbirth. As this experience could potentially trigger unpleasant memories, contact details of counselling services that specialise in pregnancy loss support were provided at the start and end of the survey. Information on data storage and consent was also included on the information sheet. Informed consent was assumed once the participants clicked 'next.'

Statistical analysis

Descriptive statistics were determined for the demographic and stillbirth history data and provided as counts and percentages. The data was screened for univariate outliers and missing items, but there was no missing data. An exploratory factor analysis (EFA) was undertaken on the 83 items using the SPSS factor-analysis procedure with principal components extraction. A four-factor solution was determined from a scree plot and initial extraction undertaken using direct oblimin-oblique rotation. The oblimin-oblique rotation was used to assess correlation between the four extracted factors. Since the correlation found was

Table 1. Demographics of sample

	n=%
Gender	
Female	94
Male	6
Age	
18-24	5
25-34	55
35-44	34
>45	6
Residing state	
South Australia	27
Western Australia	6
Queensland	10
New South Wales	32
Victoria	19
Australian Capital Territory	4
Northern Territory	2
Cultural background	
Caucasian	97
Aboriginal/Torres Strait Islander	1
Other	2
Education	
Less than a high school degree	8
High school certificate	28
Some university but no degree	18
Associate's degree	2
Bachelor's degree	27
Postgraduate degree	17

considerable, this remained the final solution, with no attempt at varimax rotation. Hair et al (1998) suggested that a cut-off for factor loadings should be 0.55 or higher with a sample size of 100. We took a conservative approach, dropping items with a factor loading <0.5. Further items with a loading slightly greater than 0.5 were also dropped if it was agreed by the authors (DP, EP, JW) that it could be omitted without affecting the theoretical understanding of the constructs. This was to create a scale that is reasonably short and thus minimising respondent burden. The minimum of data for factor analysis was satisfied (n=100) as per the guidelines suggested by Iacobucci (2010); however it is acknowledged that there are differing views on the most suitable sample size for EFAs. To create the actual scales, an additive process occurred on each sub-scale by summing the scores, and the score for the subscales combined, to provide a total score. Subsequently, reliability (Pearson's correlation coefficient) and validity (Cronbach's alpha) analysis were performed on the same data set.

Results

Initially, 162 participants started the survey, with 44 participants not meeting the inclusion criteria. A further 18

Table 2. Stillbirth history of participants

	n=%
Gestational age	
2nd trimester (20-24)	26
2nd trimester (25-27)	10
3rd trimester (28-39)	47
3rd trimester (40+)	16
Missing	1
Year of most recent stillbirth	
2013-2017	74
2012-2008	18
2007-2000	4
<1999	4

participants did not complete the survey in its entirety. Those who did not fully complete the proposed stillbirth-stigma scale were not included within this factor analysis. There were 35 respondents who left their details for test-retest and,

in total, 26 participants completed the validation, a response rate of 74.82%. Thus, the participants were 100 Australian bereaved mothers and fathers. Participants were mainly Caucasian, between the ages of 25 and 34, and primarily resided in New South Wales or South Australia. Most were married (69%, n=69). Full demographic characteristics are presented in Table 1.

The participants' stillbirth history is shown in Table 2. The majority had their most recent stillbirth within five years of this study. However, the earliest stillbirth occurred in 1980. Most stillbirths had occurred in the third trimester between 28-39 weeks. Five participants indicated that all babies from a multiple pregnancy had been stillborn. At the time of completing the survey, 21% (n=21) of the participants were currently pregnant.

Exploratory factor analysis

Four identified factors (see Table 3) accounted for 60.48% of the variance: Perceived devaluation due to stigma, discrimination, self-stigma, and disclosure. Factor loading describes the correlation of each variable to an underlying

Table 3. Factor loadings of the exploratory factor analysis

Item number	Loading	Item	Item description	Explained variance	Cronbach alpha (a)
			Perceived devaluation due to stigma	32.87	.81
1	.795	48	Most people will not say your child's name		
2	.712	45	Most people will not look you in the eye when you speak about your stillbirth		
3	.706	50	Most people will avoid discussing your stillbirth or stillborn child		
4	.688	46	Most people will accept your child as one of your own.		
5	.556	49	Most people will not look at mementos of your child if offered		
6	.539	43	Most believe that you are not a mother/father if you have had a stillbirth		
			Discrimination	12.84	.89
7	.862	5	I have been discriminated against by my friends because of my stillbirth		
8	.812	6	Sometimes I feel that I have being talked down to because of my stillbirth		
9	.801	4	I have been discriminated against by my extended family because of my stillbirth		
10	.800	33	People have insulted me because of my stillbirth		
11	.740	20	I have been emotionally abused because of my stillbirth		
12	.657	64	Nobody has been interested in talking to me since having had a stillbirth		
13	.647	31	I have been discriminated against by health professionals because of my stillbirth		
			Self-stigma	8.25	.73
14	.788	37	Having had a stillbirth makes me feel that life is unfair		
15	.679	8	I blamed myself after my stillbirth		
16	.661	65	I am disappointed in myself since having a stillbirth		
17	.634	69	I feel blemished		
			Disclosure	6.50	.80
18	.869	36	I feel the need to hide my stillbirth		
19	.804	73	I find it hard telling people I have had a stillbirth		
20	.752	16	I worry about others telling people I do not know I have had a stillbirth		
Total				60.48%	.77

Table 4. Test-retest results

N=26		Original scores		Re-test scores		
	Scoring range	Mean	Std. dev	Mean	Std. dev	Pearson correlation
Perceived devaluation of stigma	6-30	19.26	5.58	19.80	4.62	.79
Discrimination	7-35	14.77	5.07	14.27	4.97	.91
Self-stigma	4-20	13.42	3.93	13.7	3.19	.85
Disclosure	3-15	8.11	3.37	7.61	3.17	.91
Total stigma scale	20-100	55.57	13.91	55.42	11.88	.90

factor. Across these four factors, there were a total of 20 items retained for the final scales, based on the strength of their factor loadings. The first factor, perceived devaluation due to stigma, included six items and assessed the bereaved parent's perception of the negative attitudes and beliefs that affect their status as a parent and their baby's status within their respective community. The second factor, discrimination, had seven items loading on it and has the potential to identify the discriminating experiences in different social scenarios, such as family and healthcare professionals, experienced by bereaved parents. The third factor, self-stigma, had four items loading on it and reflects the extent to which bereaved parents adopt the negative attitudes that surround stillbirth. The final factor, discrimination, had three items loading on it and assesses the bereaved parent's ability to inform or discuss their stillborn child with others.

Internal consistency and test-retest reliability

The Cronbach's alpha for each factor was satisfactory (Table 3) as was alpha for the whole scale (George and Mallery, 2003). The Pearson correlation coefficient was calculated from the test-retest data for each factor and the overall scale, and the results provided in Table 4. Reliability was satisfactory for each factor and the overall scale.

Discussion

This paper aimed to describe the development and initial psychometric evaluation of a stillbirth-stigma scale. The EFA identified four factors: perceived devaluation, discrimination, self-stigma, and disclosure. Perceived devaluation due to stigma consists of 32.87% of the variance, more than double each of the other sub-scales found. Overall, the test-retest reliability coefficients were good to excellent, which suggest the scores are relatively stable. Furthermore, Cronbach alpha scores indicate that there is acceptable to good internal consistency within the scale structure.

This scale provides the necessary first steps in answering WHO and the 2011 and 2016 *Lancet* series calls to action to identify mechanisms to reduce stillbirth stigma (Horton and Samarasekera, 2016; Goldenberg et al, 2011; Scott, 2011). It addresses a gap in evidence by providing a measure of stillbirth stigma to assist in the development of stigma-reduction programs. This scale is the first to be developed specifically for bereaved parents who have endured stillbirth and it has been designed by bereaved parents. The sub-scales identified are consistent with the stillbirth experiences

endured by bereaved parents reported within the literature (Burden et al, 2016; Pollock l et al, 2019). Not surprisingly, the sub-scales in the stillbirth-stigma scale (perceived devaluation, discrimination, self-stigma, and disclosure) are consistent with the sub-scales found in the adapted scales. For example, discrimination was found within the current scale, within the mental health stigma scale and within the perceived devaluation/discrimination scale.

The first sub-scale, perceived devaluation of stigma, can be broken down into the following: what the individual thinks most people believe about the stigmatised group, and, how society views them personally as a member of a stigmatised group (LeBel, 2008). While the bereaved parent may not have directly experienced these negative attitudes, they might believe that such attitudes are present within their community.

Stigma is seen as a power mechanism to keep people down (Link and Phelan, 2014, Link and Phelan, 2001). Discrimination is therefore a core feature of the stigma experience and a consequence of believing the attitudes and beliefs surrounding a stigmatised condition (Link and Phelan, 2001). Discrimination is a common sub-scale found within stigma scales, especially in mental health (Brohan et al, 2010). Brohan et al's (2010) review of stigma measures found 50% of their 24 measures identified included discrimination. The items within the discrimination subscale of the current study mostly explore the individual stigma felt by the bereaved parent. Although discrimination and stillbirth have not been explicitly investigated nor reported, there are several examples of bereaved parents enduring discriminating behaviours (Pollock at al, 2019a). The most common is the bereaved parent's perception that they have suffered a status loss due to their stillbirth (Brierley-Jones et al, 2015: Pollock et al, 2019a).

Self-stigma, otherwise known as internalised stigma, explores the internalisation of the labels and stereotypes associated with a stigmatised condition. It is a common sub-scale with many stigma scales in existing fields; for example, the internalised stigma of mental illness (ISMI), and depression self-stigma scale (DSS) (Brohan et al, 2010). Items within this sub-scale include bereaved parents feeling blemished, disappointed or blaming themselves after their stillbirth. Within the stillbirth literature, there is a plethora of research that has found examples of bereaved parents self-stigmatising; these include experiences of shame and blame (Murphy, 2012b; McCreight, 2004).

Disclosure closely relates to self-stigma, but is a stigma

management technique, to maintain the impressions that a stigmatised individual leaves within their community. It is a conscious decision by the stigmatised to conceal their stigmatising identity (Goffman, 1968). The choice to disclose is complex; to reveal a stigmatised condition can have ramifications such as discrimination. However, not disclosing can have adverse effects on the individual's mental health, including lower levels of self-esteem and social support (Hult et al, 2010), although this relationship remains inconsistent within the literature (Smith et al, 2008). Disclosure has been included in prior stigma scales, including the stigma scale that focuses on mental health (Brohan et al, 2010).

Strengths and limitations

One strength of this study is the active involvement of those with a lived experience of stillbirth (JW is a midwife and researcher; DP is a social scientist; and Claire Foord is a consumer advocate and CEO of Still Aware, all of whom have experienced a stillbirth) in the development of each item, the analysis and interpretation of the results, and the write up. It allowed for the development of the first scale to measure stillbirth stigma to be relevant to the bereaved parent and supported by empirical evidence.

There are several limitations associated with this study; the first is sampling issues. The current study has a high proportion of Caucasian and highly educated women. Despite best efforts, it did not capture the experiences of many bereaved fathers (n=6), which is a common issue within stillbirth research. The current study has also not captured the stigma experiences of the indigenous populations such as Australian Aboriginal or Torres Strait Islander peoples or bereaved parents from other culturally and linguistically different (CALD) backgrounds. The experience of stigma can be dependent on the cultural background of an individual, and therefore, until further validation has occurred, the developed scale may not be applicable to these populations.

Furthermore, to allow for an inclusive approach to this study, there was no time limitation stipulated on how long ago the stillbirth occurred. Twenty-four (24%) of the participants had experienced a stillbirth more than five years before the study was commenced, with the earliest stillbirth noted occurring in 1980. Therefore, their recollections may be subject to recall bias. However, according to Clarke et al (2008), this may not be of concern as including these participants adds richness to the study by understanding the changing attitudes and perceptions of stillbirth.

They may also have had longer exposure to potentially stigmatising events than those recently bereaved and this may also affect the utility of the scale. Those participants can

therefore play an important role in helping to determine if stillbirth stigma can be affected by time.

Future research

Further development through additional testing on the stillbirth-stigma scale needs to occur, with a larger and more diverse sample size. This will enable a confirmatory factor analysis to be conducted to further determine the reliability and validity of the stillbirth-stigma scale. Recruitment that specifically targets bereaved fathers is crucial in understanding the stigma experiences they could potentially be enduring. The father's stigma experience is necessary to determine if interventions should be targeted to specific genders to reduce stillbirth stigma. Furthermore, research is needed to determine if the stillbirth-stigma scale can potentially determine predictors for those bereaved parents who may endure higher rates of stigma.

Clinical implication of the Stillbirth-stigma scale

Further research on the validity and reliability of the stigma scale needs to occur, especially in a clinical setting, before any implications can be identified In its current state, it may provide understanding to healthcare providers, not-for-profit organisations and government agencies on the experience of stigma endured by bereaved parents.

Conclusion

Despite several calls for the stigma of stillbirth to be addressed and research that provides examples of bereaved parents enduring a stigmatising environment, there have been no prior studies that attempted to measure the extent or the type of stigma associated with stillbirth. By developing and piloting the Stillbirth-stigma scale, the current research has created a scale that is consistent with existing stigma scales in other fields, while also understanding the unique stillbirth experience endured by bereaved parents. The Stillbirth-stigma scale is statistically sound, with four constructs (perceived devaluation, discrimination, self-stigma and disclosure) determined from an extensive search of the literature, adaptation of existing scales and discussion with those who have had a lived experience of stillbirth.

However, further research needs to be undertaken to ensure the validity of the Stillbirth-stigma scale as a reliable measurement. In the longer term, it is anticipated this measurement tool will be useful in providing government, non-government agencies, organisations that support bereaved parents after stillbirth, and clinicians in understanding the impact of stigma as well as informing the development of stigma-reduction strategies.

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Perspectives of youth-support professionals on encouraging healthy eating in adolescent pregnancies

Professor Hora Soltani[1] BSC, MMedSci, RM, PGDip, PGCert, PhD Katie Marvin-Dowle[2] BMedSci, PGCert, MPH, PhD Dr Victoria Burley[3] BSc, MSc, PhD.

1. Professor in Maternal and Infant Health, Centre for Health and Social Care Research, Sheffield Hallam University, Collegiate Crescent, Sheffield, S10 2BP. H.soltani@shu.ac.uk
2. Midwifery Researcher, Centre for Health and Social Care Research, Sheffield Hallam University, Collegiate Crescent, Sheffield, S10 2BP. K.marvin-dowle@shu.ac.uk
3. Consultant in Nutritional Science, c/o Centre for Health and Social Care Research, Sheffield Hallam University, Collegiate Crescent, Sheffield, S10 2BP. vburleynutr@gmail.com

Abstract

Background. Nutrition during pregnancy has been identified as an important modifiable factor to reduce adverse outcomes in adolescent pregnancies. Young women are supported during their pregnancies by a variety of professionals with both clinical and non-clinical roles. Professionals with a non-clinical support role provide practical and emotional support for young women and often have longer lasting professional relationships with their clients. For this reason, this study aims to explore the perspectives of these professionals on how young women can be encouraged to improve their diet during pregnancy.

Ethics. Ethical approval for this study was granted by Sheffield Hallam University Ethics Committee in July 2016.

Methods. This exploratory, qualitative study recruited eight youth-support professionals to take part in semi-structured interviews. Recruitment and interviews were conducted by the lead author during February 2017, with project supervision and triangulation of data completed by the other two authors. Interviews were audio-recorded and transcribed. Interview transcripts were loaded into NVivo 11 software to facilitate analysis and emerging themes identified.

Results. Five overarching themes were identified from the data: perceptions of dietary pattern; connection with baby; family and social stability; building relationships; and service availability. Youth-support professionals felt that young women encountered numerous complex barriers to eating healthily during pregnancy. Their lives are frequently chaotic and lack a stable partner and family relationships. They suggested that young women often needed specific practical support to make improvements, such as being accompanied to health appointments. There was also some concern that further cuts to services for this group would make it more difficult for vulnerable young women to access help.

Conclusions. A higher level of consistent, holistic support delivered by joined-up networks of professionals is needed to help young women achieve healthier pregnancies. Further research is necessary to understand the context of young women's lives, how this relates to their experiences of pregnancy, and what type of interventions or resources would have the biggest impact in supporting healthy behaviours.

Keywords: Adolescent, pregnancy, nutrition, healthy eating, youth work, evidence-based midwifery

Introduction

Pregnancy during the adolescent years (age 19 and under) has often been associated with higher rates of adverse outcomes for mother and baby compared with women aged 20-35. This is the case both in terms of social issues, such as isolation and poverty (Cook and Cameron, 2015), and clinical outcomes, such as low birthweight and prematurity (Tyrberg et al, 2013; Gilbert et al, 2004). Women aged over 35 also face age-related pregnancy challenges, particularly in clinical outcomes (Kenny et al, 2013), however this is not the focus of the current paper.

Under-18 conception rates in England and Wales have been declining steadily with a 5.3% decrease between 2016 and 2017 to 17.9 conceptions per 1,000 women aged 15 to 17 years. However, the proportion of rapid repeat pregnancies (defined as a second birth within two years of a previous birth) in this group is high, between 12-25% (Public Health England, 2018) and those who become pregnant at a young age are most likely to be vulnerable to poor social outcomes (Whitaker et al, 2014).

Work to assess the mechanisms by which early pregnancy increases the risk of poor outcomes has suggested that maternal nutrition may be an important modifiable factor.

A systematic review by Gibbs et al (2012) looking at the relationship between adolescent pregnancy and pregnancy outcomes found that very young maternal age had a negative effect on fetal growth and infant survival. The authors suggested that there may be competition between the baby and the mother, who is also still growing, resulting in babies with low birthweight or who are small for their gestational age.

A further systematic review of nutrient intakes and nutritional biomarkers in adolescent pregnancies found that intakes of energy, fibre and a number of key micronutrients were below recommended levels (Marvin-Dowle et al, 2016). Assessment of nutritional biomarkers also suggested there may be some cause for concern with regard to iron and selenium status.

Assessment of the dietary patterns of pregnant adolescents in the Born in Bradford cohort (Marvin-Dowle et al, 2018a) found that young women had higher intakes of snack and processed foods, which were high in salt, sugar and saturated fats, compared with older pregnant women. The study also found that adolescents had higher intakes of sugar-sweetened cola and lower intakes of fruit, vegetables and nutritional supplements.

The evidence presented suggests that pregnant adolescents are likely to have a diet that is nutritionally poor and also that this may have an impact on the health of their unborn baby. It is therefore important to understand more about the nature of adolescent diets and how they can be supported to make positive changes during pregnancy, including assessing the barriers and conflicting priorities faced by women in this group.

One survey of young women and healthcare professionals (HCPs) regarding dietary habits and supplementation practices during pregnancy (Soltani et al, 2017) found that young women did report making some positive changes to their diet during pregnancy, citing the impact on fetal development as the primary reason.

The same study also collected responses from HCPs, including midwives, family nurses and health visitors, regarding their discussions with young women around diet and nutrition during pregnancy. Family nurses were more likely to discuss nutrition in greater depth with young women due to time constraints on midwife and health-visitor appointments. Young women stated that they mostly prefer receiving advice and information from HCPs, with mixed responses for other sources including websites and apps, leaflets, family members or parenting classes. HCPs reported that young women often struggled to access Healthy Start vouchers or vitamins. Pregnant adolescents with otherwise uncomplicated pregnancies in the United Kingdom (UK) will receive standard National Health Service (NHS) antenatal care as a minimum (NICE, 2008). Additional services for this population are commissioned locally and therefore vary among NHS Trusts. The area in which this research has been conducted has previously had both teenage pregnancy specialist midwives and family-nurse partnership services; however these services have been decommissioned at the time of writing.

HCPs are not the only people who have a role in supporting young women during pregnancy in the UK. Pregnant adolescents are at increased risk of being socially isolated or experiencing difficulties with housing or access to education and training (Cook and Cameron, 2015). They are also more likely to have experienced being cared for by a local authority (Craine et al, 2014). This means that a significant proportion of young women who become pregnant will have contact with professionals such as youth workers and support advisors who are likely to spend more time with young women than HCPs, whose appointment times are limited. These relationships are largely voluntary on the part of young people and some young women will have difficulties accessing support services, meaning that this type of additional support is far from universal. That said, professionals who work in these roles have a unique insight into the experiences of young women during pregnancy and how they may be best supported to have healthy pregnancies. It is therefore this group who are the target for this study.

There is increasing recognition that there are a number of wider determinants beyond the availability of healthy food and the food environment that affect the diets of individuals, including socio-economic deprivation, housing, employment, education and physical and mental health (Baumann and Kaiser, 2018). This suggests that for pregnant adolescents the barriers to healthy eating are multi-faceted and require broad consideration. For this reason, while the focus of the present study is adolescents' diet during pregnancy, the study also aims to consider the broader context of young women's lives, which also has an impact on their ability to achieve a healthy diet.

Aims
The two research questions this study aimed to address were: 'What do youth-support professionals perceive to be the barriers and facilitators to healthy eating for pregnant adolescents?' and 'How do youth-support professionals think young women can be best supported to have a healthy diet during pregnancy?'

Methods

Design
This exploratory, qualitative study used semi-structured interviews to gather information from professionals with a role in providing social or practical support to young women during pregnancy. Professionals whose main role was clinical, such as midwives and health visitors, were excluded, as the views of these professionals, alongside those of young women, have been sought previously (Rundle et al, 2018). All participants worked in Sheffield, which is a large city in northern England. The interviews took place locally at a time and location convenient to the participants.

Characteristics of the research team
This study was undertaken as part of a PhD programme of work. All of the recruitment and interviews were conducted by the lead author during February 2017, with project supervision and triangulation of data completed by the other two authors.

Participants and recruitment
Participants were recruited via email invitations sent to relevant agencies, hard-copy flyers distributed to services, social media, and word of mouth. As this was intended to be an exploratory piece of work, eight to 10 participants were deemed adequate to assess the issues considered to be most important by participants. Individuals were eligible to take part if they had a professional role supporting young people and had some experience of working with young women (aged ≤19) during pregnancy. Participants were contacted prior to the study, after having expressed interest in taking part, in order to arrange appointments to meet. Participants were aware that the study was part of a PhD programme and that the focus was on supporting healthy pregnancies in adolescents.

Ethical considerations
Participants were self-selected by responding to recruitment materials circulated in their place of work. The purpose and scope of the project was explained to participants both at the time of recruitment and immediately prior to the interview, ensuring that the consent they provided was fully informed. Participants were given a participant information sheet and the opportunity to ask any questions at least 24 hours

Table 1. Participant characteristics

	Job role	Gender	Age group	Highest qualification	Number of children	Individual or shared interview
P1	Parenting-support worker	Female	26-35	A-level or equivalent	0	Shared
P2	Parenting-support worker	Male	Not reported	Not reported	Not reported	Shared
P3	Youth-support worker	Female	26-35	Degree or equivalent	1	Shared
P4	Education officer	Female	36-45	Degree or equivalent	2	Shared
P5	Youth-project manager	Female	46-55	Degree or equivalent	4	Individual
P6	Youth-support advisor	Female	36-45	Degree or equivalent	2	Individual
P7	Youth-support worker	Female	36-45	A-level or equivalent	1	Individual
P8	Perinatal-support co-ordinator	Female	36-45	A-level or equivalent	3	Individual

ahead of being asked to sign a consent form. Interviews were audio recorded and transcribed verbatim with any identifying information removed, following which the audio files were destroyed. This process ensures that individuals are not identifiable from the data and their confidentiality is maintained. Consent forms containing participant's personal details have been stored securely and will be destroyed when they are no longer needed. Ethical approval for this study was granted by Sheffield Hallam University Ethics Committee in July 2016.

Data collection
Semi-structured interviews were carried out either on a one-to-one basis or with two participants together who worked in the same agency (two interviews). Participants were also asked to complete a brief demographic questionnaire.

A topic guide was developed that was informed by previous quantitative work carried out during the PhD study. This work has been published elsewhere (Marvin-Dowle et al 2018a, Marvin-Dowle et al 2018b, Marvin-Dowle 2016) but, in brief, the results suggested that the dietary patterns and nutritional status of pregnant adolescents is likely to be poorer than that of adult women. They are also more likely to experience higher levels of poverty, lower education and their babies may be at higher risk of adverse outcomes. The topic guide for this study therefore covered these main topic areas. The topic guide is detailed as Appendix 1. Interviews were audio recorded with participants' consent.

Data analysis
Audio recordings of interview data were transcribed verbatim and transcripts anonymised with participants being allocated a participant number for identification purposes. Transcripts were loaded into NVivo 11 software to facilitate analysis. Data analysis was carried out inductively using thematic analysis which involved familiarisation with the data, generation of initial codes, assigning coded data into related categories and developing overarching themes (Braun and Clarke, 2006). Initial analysis was conducted by one researcher and codes and themes verified by a second researcher to enhance inter-reliability.

Results

Participant characteristics
A total of eight participants took part in six interviews; four of the interviews were individual and two interviews took place with two colleagues from the same agency at the same time. Characteristics of the participants are shown in Table 1. The majority of participants were female, aged 26-45 and had experience of being parents.

Analysis of interview transcripts identified five over-arching themes within the data: perceptions of diet; connection with baby; family and social stability; building relationships, and service availability. Sub-themes were also reported where these added clarity and depth to the data.

Perceptions of diet

Concerns over poor diet
All participants discussed the content of young women's diet during pregnancy and expressed concern over the dietary patterns they observed within their client group. Participants perceived the majority of young women ate a large amount of fast/junk food, snacks that are high in salt, sugar and fat alongside sugary and/or highly caffeinated drinks and very little fresh produce or home cooked meals.

P5: *"And they're overeating, every pregnant girl we see has just got energy drinks and chocolate and you know their diet is so phenomenally bad."*

P3: *"...their diets weren't particularly fantastic, it was just eat whatever, you know, junk food."*

Concern over poor dietary patterns was a common theme across all of the interviews. Some participants did mention young women who ate more healthily or made a particular effort to change their eating habits, however these young women were singled out as unusual or as an exception to the rule.

P7: *"I've got my lady who just had a baby a few weeks ago, took the health of herself and the unborn child really seriously, she had low iron so made sure she bought really high iron foods, and really got that link, so it's a bit hit and miss."*

P6: *"...one is super health-conscious and she'll make home-cooked food, beautiful food as well, and the other one's like, meh, whatever."*

Lack of sufficient knowledge or information
One participant said that young women were often confused about which foods should be avoided during pregnancy, and also mentioned that they did not have sufficient knowledge or reliable information on this subject.

P5: *"Then, when they do come to places like this, they're asking questions like: 'Can I eat mayonnaise?' There's still confusion."*

There was a sense that young women were less knowledgeable and less prepared for the pregnancy than older women in terms of diet and nutritional supplements to support the pregnancy. This was presented almost as a dichotomy by one participant who suggested the older women would have significantly more knowledge than adolescents.

P4: *"It's not like for older women getting pregnant and knowing exactly what you're supposed to be eating, what you're not supposed to be eating, take your folic acid and all of that…"*

Connection with baby
All participants talked about their perceptions of young women's readiness or motivation to make changes to improve their own health and that of their baby. A key theme related to behavioural change was the importance young women gave to healthy eating. The majority of participants reported that they didn't think the young women they worked with felt their nutrition was important.

P3: *"I don't feel I'm discussing with them that they feel that's [diet] important at all."*

P4: *"We used to go through what they should be eating, what was going to be good for them and the baby… it wasn't on the top of their priority list."*

There was a regular theme across the data which suggested that the participants felt that some young women struggled to see their baby as really there before the birth. This meant that these young women did not necessarily connect their behaviours with the health of their unborn baby, particularly with reference to diet.

P8: *"It's a hard one because we've come across mums who don't actually see baby as being there until the baby is actually in their arms."*

P5: *"Breastfeeding and healthy eating… I don't think that connection is there at all."*

This was linked to ideas put forward by several participants that the young women they worked with were not always emotionally mature enough to make decisive changes or to accept the significant changes that were happening to them as a result of the pregnancy. As with the comments on diet content, however, there were exceptions where participants spoke of young women they had worked with who had made positive changes, but these were much less common than references to young women who either did not try to make changes or who struggled to do so.

P1: *"There's some 17-, 18-year-old mums we've worked with [who are] really switched [on]…but I think sometimes that a big barrier to a healthy pregnancy is a willingness and acceptance that things have to change."*

P2: *"Somebody who's a bit older might be more emotionally ready, and ready to make those changes… I think sometimes, with not all but some, it's the maturity of focusing and thinking: 'Right, I need to do that.'*

Family and social stability
The majority of young women that the participants were involved with faced significant challenges, both in terms of their historical family situations and current living arrangements.

Family support and growing up in care
A number of the participants spoke about the difficult family backgrounds their clients had come from, including high levels of poverty, unstable families and that a significant proportion of the young women they worked with had spent time being looked after in local authority care.

P6: *"A lot of the issues for our young people are because they've not had any positive parenting in their formative years, so they've not grown up with good routines, they've come from abused backgrounds, so they don't always understand what a good parent is and what they should do."*

P7: *"Most of these kids don't have stable families and as a mum myself I know you need your family when you have a baby."*

It was also suggested that experiences of being removed from families and being placed in local authority care may influence young women's willingness to seek or accept support, particularly from social services, for fear that their own children may be removed from their care.

P8 *"Remember these young people have been removed from their families; their automatic fear is that you're there to do the same."*

It was also discussed how unstable family situations may have contributed to a lack of knowledge and skills around healthy eating and cooking, in that young women may not have had role models available to them or have been taught how to prepare and cook healthier meals.

P1: *"They've probably not built those skills up to care for themselves in a heathy eating sort of way."*

Housing and poverty
Young women's current living situation was also a common theme with the majority of participants talking about young women living in poverty and experiencing housing issues. Being able to provide a safe and appropriate home for their baby was discussed as being clearly important to young women and a significant source of stress.

P7: *"I've just had a lady who gave birth about four weeks ago and she moved house two weeks before she gave birth. I was there until seven or eight o'clock at night helping her get everything ready, and as soon as, she'd moved in and got everything sorted, the baby arrived."*

The situation of living in poverty was also considered a barrier to eating well by some participants, as healthy food was considered to be prohibitively expensive.

P5: *"How are they supposed to eat healthily if they've got no extra money, have you seen the price of fruit? You know, it's ridiculously overpriced."*

One participant also suggested that promotions on less healthy foods made it difficult for young women to make healthier choices.

P5: *"Our teenage parents will come in with all kinds of rubbish and you think 'Jeez', but when they're offering four doughnuts for a pound, why wouldn't you?"*

Social support and isolation

Difficult personal relationships, particularly with partners/baby's father were discussed by all of the participants. Young women were described as being very heavily influenced by their partners. Young fathers were described as either a negative, controlling influence or as absent.

P4: *"Their boyfriends are a massive influence on them, on the decisions they make about breastfeeding, stopping smoking, getting their figure back, starting to have sex again. They're very dominated by their partners."*

P1: *"With breastfeeding, so many of the girls I worked with weren't going to try it at all because their partners were very much 'you don't feed the baby, your breasts are a sexual thing.'"*

P5: *"I could probably count on one hand the ones that have stayed with their partners out of 350 girls… After six weeks the girls are left on their own."*

Similar issues were described with young women losing friends after having a baby as their priorities changed, leading to new mothers becoming increasingly isolated and without support.

P5: *"It's the age-old you know… all my friends are going to come round and visit… You know that after six weeks your friends will disappear and so will your boyfriend."*

Isolation and mental health issues – compounded by this lack of support – were very prominent themes identified from the data. Some participants spoke about how many of their clients had mental health issues that were present before pregnancy and which clearly had an effect on their wellbeing and ability to cope with a pregnancy.

P3: *"Most had complex needs in terms of their health and mental health already that weren't being addressed."*

For others, the stress and pressure of the pregnancy and parenthood, connected to the difficult living situations the young women were in, meant that mental health issues were almost inevitable.

P8: *"A lot of the ladies that I work with are single mums with no family, no support and are very isolated… to think if you are pregnant at 16, 17, 18, 19 it's quite scary not having anybody there."*

There was a sense that young women actually do incredibly well to cope with pregnancy and motherhood in the context of chaotic lives, and that often more is expected of young parents than is possible given the reality of their situation.

P7: *"I think we expect these young people that have got post-traumatic stress disorder or, you know, lots of really significant abuse in their life, to just function as an everyday parent in life. And a lot of them do, don't get me wrong, I've got loads of success stories, but sometimes they're tired and just need a break."*

Building relationships

The participants spoke extensively about their own roles in supporting young women, how they worked with other agencies and where they felt services were lacking or falling short of providing what is necessary. The participants generally saw their role as separate to that of clinical health professionals, but that didn't mean they were not concerned with the health of the pregnancy.

P5: *"We're not social workers or midwives, we're youth workers and we come from a different perspective."*

Building relationships with young women was considered central to their work, and it was suggested that this may be more challenging due to young women's backgrounds.

P2: *"They've got to build up that trust in professionals and people that are trying to support them… someone who's never had that ability to have a trusting relationship with an adult; you've got to build that trust."*

P3: *"Often, it's about relationships, hand-holding, transition and actually getting to places."*

Most of the participants also spoke about providing practical support, particularly in facilitating young women to attend health appointments, which were often missed, leading to potential consequences for the health of the pregnancy.

P3: *"We make assumptions they've got access to services – therefore they access them… some of those health needs we assume are being addressed, but they're not because, just on a basic level, they're not accessing appointments."*

P4: *"I think our role mainly is to ensure that they're getting access to the services that they should be getting."*

Service availability

There was also a significant amount of discussion in every interview about the need for more resources and the impact of cuts to existing services. All of the participants considered that cuts to services had a detrimental effect on young women's health during pregnancy.

P5: *"They used to have, several years ago, specialists that, once a girl found out she was pregnant, was put straight on to her. First round of cuts… that was the first thing that went."*

P6: *"I mean the family-nurse partnership… they were quite key in supporting the girls and building that relationship with them, and they used to refer them to us, and now they've gone."*

When asked about whether additional resources would be helpful the majority agreed that an information resource that gave universal information and also provided local signposting would be useful, and that this would need to be provided in multiple formats.

P3: *"It would definitely be helpful, if we had some kind of, like we used to have at the young women's unit, a place where young pregnant women could drop in and get the support and the advice."*

P4: *"I think you'd need to cover all of those [formats], I mean definitely use technology, something they could easily download on their phone or they could come in here and have somebody sit and go through with them like a physical paper pack."*

Overall, the overwhelming message from the data was that the participants recognised the importance of supporting healthy eating as part of a healthy pregnancy and supported young women to do their best in often particularly difficult circumstances. There are significant concerns, particularly around young women's mental health, and dedicated, specialised services are needed for any significant improvements to be made.

P7: *"It would be nice to have a central point we can tell: 'I've got a pregnant mum, this is what we need to do.'"*

P4: *"If you could just ask to get a new service for pregnant teenagers back that'd be great, that's all we want, that'd be really good."*

Discussion

Key findings

This study is novel in that it seeks to gather the perspectives of a professional group that has not been consulted before on the topic of improving health in adolescent pregnancies. Integrated models of care that bring together social support services and primary healthcare in the UK are rare. One example of such a service is the Well Centre in South London (Hagell and Lamb, 2016), which is designed to be a 'one-stop-shop' for adolescents. Evaluation has shown that young people were accessing the services who were not engaged with any other service, particularly those with mental health needs. This suggests that collaborative work between primary care services and youth-work providers may facilitate the most vulnerable young people to access and engage with the services they need; although the effectiveness of such services requires robust independent evaluations.

In this research, nutrition was a topic that was generally considered to be important by youth-support professionals, however they perceived that this view was not necessarily shared by the young women they worked with. The majority of participants in the present study perceived that the young women in their care ate large amounts of take-away and processed foods and sugary drinks, and little fruit or vegetables. This is largely consistent with existing literature suggesting that adolescent's diet during pregnancy is often poor (Marvin-Dowle et al, 2016; Marvin-Dowle et al, 2018a; Northstone et al, 2008; Scholl and Hediger, 1995). While the present study was only able to report the thoughts and perceptions of youth-support workers, the findings of larger, quantitative studies suggest that the perceptions of the participants have been empirically confirmed. The latest wave of the National Diet and Nutrition Survey (NDNS) produced by Public Health England (2018) from the 2014/15 to 2015/16 surveys found adolescent girls reported consuming an average of 2.8 portions of fruit and vegetables a day compared with 4.2 portions for adult women. Young women also consumed almost twice the amount of sugar-sweetened beverages compared with adult women (183g and 100g respectively). This suggests that it is not just pregnant adolescents but in fact the majority of young women who have a poor diet. While the immediate consequences may be more apparent for young women who are pregnant, this does suggest population-wide interventions are needed to improve nutrition in all adolescents.

Reasons suggested for poor diet in pregnant young women were varied and included lack of interest or belief that nutrition makes a difference, lack of knowledge and skills, and the price of healthier choices. Participants spoke about how they believed young women often didn't make the connection between themselves and their baby until after the baby was born, particularly with reference to how their dietary intake might affect the developing foetus. Previous research has shown that a mother's emotional connection with her child during pregnancy can have a significant impact on her health behaviours. The theory of maternal-fetal attachment (MFA) proposed by Cranley (1981: 282) is defined as "the extent to which women engage in behaviours that represent an affiliation and interaction with their unborn child" and the validated tool has been used to explore connections between attachment and maternal health behaviours. One study exploring correlations between MFA and comprehensive measures of pregnancy health behaviours (including balance of rest and exercise, safety measures, nutrition, avoiding use of harmful substances, obtaining healthcare, and obtaining information) in low-income urban women (Alhusen et al, 2012) found an overall positive association between women's scores on the two measures. This suggests that improving women's emotional connection to the developing fetus may in turn improve health behaviours.

Psychosocial stability, lack of social support and isolation were themes which emerged clearly from this data set as barriers to achieving a healthy diet. Mental health needs are likely to be high in this population as they are associated with neglect or abuse during childhood (Mills et al, 2013), which is a likely contributor to young women being looked after in local authority care. This suggests that pregnant and parenting adolescents are at higher risk of experiencing mental health problems compared with older mothers (Siegel and Brandon, 2014). This is an important observation in the context of this study due to the impact that poor mental health may have on young women's ability to eat well and look after their own wellbeing.

Poor diet has also been correlated with poor mental health in adolescents (Kulkarni et al, 2015; O'Neil et al, 2014) suggesting that improvements to young women's mental health may in turn help them to improve their diet.

The price of healthy food such as fruit was cited as a significant barrier to eating well and that young women favoured cheap, high-energy density snack foods that were often subject to price promotions. There is significant evidence to suggest that socioeconomic deprivation is associated with poorer nutritional status, particularly in adolescents. One study looking both at the attitudes and behaviours of adolescents towards healthy eating found that while participants had similar attitudes to healthy eating, regardless of socio-economic position, those from more deprived areas were more likely to report higher intakes of fast foods and sugar-sweetened soft drinks (Utter et al, 2011).

Recommendations

It has been suggested that collaborative work between primary care services and youth-work providers may facilitate the

most vulnerable young people to access and engage with the services they need; however the effectiveness of such services requires robust independent evaluations. Further work including the perspectives of other professionals working with young people, such as teachers and social workers, would help to develop a more complete picture of the support available for young women.

There is a significant lack of evidence in the literature evaluating whether young women make connections between their diet during pregnancy and the health of their baby, suggesting that this is an important area for further research. One small study (Whisner et al, 2016) reported that the majority of pregnant teenagers recognised that diet during pregnancy was important, but that this did not necessarily translate into making positive changes. A further recent study (Rundle et al, 2018) found that the desire to deliver a healthy baby was a prime motivator for pregnant young women and therefore that the benefits of making dietary changes should be framed in those terms. This study also reported young women making some small positive changes to their diet despite barriers to doing so.

Further, more in-depth, work to examine how young women view health during pregnancy, and the factors that would support or motivate them, is essential to our understanding of how to improve outcomes for young mothers and their babies.

The main message regarding improving the health and wellbeing of young women during pregnancy gained from this study was that more targeted support services are needed to meet the needs of a vulnerable population. While physical resources were considered a useful tool for health promotion, having somebody to talk to with a holistic view of health and wellbeing was considered to be the key to making improvements. This, along with greater levels of consistency in the messages that young women receive regarding how to make positive changes to their diet, are key in developing practical strategies to support young women.

There is a wealth of research addressing approaches to sexual health promotion and preventing teenage pregnancies (Mezey et al, 2017; Sorhaindo et al, 2016; Oyedele et al, 2015), including the prevention of second pregnancies (Aslam et al, 2015), however, evidence looking at strategies to support the health of young women during their pregnancy is severely lacking in the academic literature.

Limitations and risk of bias

This study is limited by the small number of participants. However, the use of qualitative methods means that the depth of the data is central to the research design. This study also does not include the perspective of pregnant young women themselves. This study was designed to complement a programme of work in which the opinions of pregnant young women and young mothers have been explored (this has been reported elsewhere (Soltani et al, 2016; Rundle, Soltani and Duxbury, 2018).

There was a potential risk of bias in that participants volunteering to take part in the study were likely to have a

particular interest in the subject. The option for colleagues to take part in joint interviews, while maximising the number of participants, may have influenced the responses of the four participants who took part in joint interviews.

It is also important to note that the researcher conducting the interviews was herself pregnant at the time of data collection. While every effort was taken to disguise the pregnancy until after interviews had taken place, the possibility that participants may have suspected the interviewer was pregnant may have affected their responses.

Conclusion

This study adds to the body of work exploring how young women's pregnancy outcomes could be improved through dietary changes. The findings suggest that for many young women in this population there are numerous, complex factors that have an impact on their ability to have healthier pregnancies. A higher level of consistent, holistic support delivered by joined-up networks of professionals is needed to help young women achieve healthier pregnancies. Further research is necessary to understand the context of young women's lives, how this relates to their experiences of pregnancy and what type of interventions or resources would have the biggest impact in supporting health behaviours.

Appendix 1: Interview topic guide

What do you think are the main issues for pregnant young women in relation to their health?
Describe how you see your role in supporting young women to have healthy pregnancies.
What do you think are the key barriers for young women?
What do you think are motivating factors?
How important do you think nutrition is to pregnancy health?
How important do you think young women feel what they eat is?
How confident do you feel giving advice to young women on health topics? On nutrition?
Are there any areas you would like additional training/ information on to improve your confidence?
What format would you like to receive information in?
Anything to add?

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Healthy backs in pregnancy: an online survey of women's lived experiences of pregnancy-related low back and/or pelvic girdle pain

Sarah Dianne Liddle[1] PhD, BA, BSc, PgCHEP, fHEA, MCSP, MAACP. Julie EM McCullough[2] PhD, BSc, PGDip. Marlene Sinclair[3] PhD, MEd, BSc, RNT, RM, RN. Ciara M. Hughes[4] PhD, BMedSc, MMedSc.

1. Lecturer in health and rehabilitation sciences, Institute of Nursing and Health Research, School of Health Sciences, Ulster University, Shore Road, Newtonabbey BT37 0QB Northern Ireland. Email: sd.liddle@ulster.ac.uk
2. Post doctoral researcher, Institute of Nursing and Health Research, School of Health Sciences, Ulster University, Shore Road, Newtonabbey BT37 0QB Northern Ireland. Email: j.mccullough@ulster.ac.uk
3. Professor of midwifery research, Institute of Nursing and Health Research, School of Health Sciences, Ulster University, Shore Road, Newtonabbey, BT37 0QB Northern Ireland. Email: m.sinclair1@ulster.ac.uk
4. Lecturer in clinical physiology, Institute of Nursing and Health Research, School of Health Sciences, Ulster University, Shore Road, Newtonabbey BT37 0QB Northern Ireland. Email: cm.hughes@ulster.ac.uk

Abstract

Background. Low back and pelvic girdle pain are largely considered normal, common complaints in pregnancy. However, associated leg pain is not well understood and requires further exploration.

Purpose. To investigate the incidence of pregnancy-related low back and pelvic girdle pain and associated symptoms.

Study design. An online cross-sectional questionnaire.

Methods. The design was exploratory and the sample was retrospective. An online questionnaire was developed using Qualtrics® software and was hosted on a university website and the Doctoral Midwifery Research Society website (doctoralmidwiferysociety.org). Popular mother and baby websites, based on the top internet search results, including Netmums, Mumsnet and Bounty, also advertised the study. Women who had given birth in the past two years were eligible to take part. Data collected included demographics, pain location and associated symptoms. This study was partly funded by The Northern Ireland Translation Research Group for Child Health. It was reviewed and approved under arrangements for Research Governance at Ulster University (Filter Committee Ref: 110111).

Results. Of 332 women who consented to participate, 191 fulfilled the eligibility criteria, and 176 submitted their responses. Respondents represented all four UK countries. A total of 157 completed the section on 'history of low back/pelvic girdle pain'; 70% (n=110) had a history of low back and/or pelvic girdle pain lasting for more than one week, while 104 women experienced low back pain (n=49) or a combination of both complaints (n=55). The intensity and the bothersomeness of low back pain was significantly greater than pelvic girdle pain during and for up to two years after pregnancy. More than two-thirds reported leg symptoms. Only six women experienced pelvic girdle pain alone, none of which reported associated leg symptoms.

Conclusions. Sixty-four percent (n=101) reported leg symptoms. These findings support current evidence of the consistent presentation of these complaints during pregnancy, and suggest that low back pain alone, or in combination with pelvic girdle pain, is more often associated with lower limb symptoms. To our knowledge, this is the first study to report the extent of lower limb involvement in pregnant women with these complaints and highlights the need for further investigation into the resultant short and longer term morbidity.

Keywords: Low back pain, pelvic girdle pain, leg symptoms, pregnancy, online survey, evidence-based midwifery

Introduction

Low back pain (LBP) and pelvic girdle pain (PGP) during pregnancy are common and can range from minor discomfort to being completely debilitating (Nacir, et al, 2009). Prevalence has been reported to range from 66% to 71% (LBP) and 20% to 64% (PGP) (Liddle and Pennick, 2015; Kovacs et al, 2012), with a typical increase in symptoms as pregnancy progresses (Nazik and Eryilmaz, 2014; Vermani, et al, 2010). Symptoms have been reported to persist at a rate of up to 43% six months after giving birth, and both continue to have an impact on the daily lives of 65% of women up to two years after delivery (Bergström et al, 2014). Gutke et al (2008) found that women with a combination of LBP and PGP were more likely to experience continued pain after delivery than those who had only LBP or PGP. Furthermore, women who had a combination of LBP and PGP during pregnancy had an 85-90% risk of experiencing symptoms in subsequent pregnancies (Persson, et al, 2013;

Vermani et al, 2010). Therefore, this condition is not limited to the antenatal period and can result in ongoing physical and psychological problems for women and their families. Bergström et al (2014) stated that, given the prevalence and effect it has on pregnant and postnatal women, LBP and PGP must be considered a complication of pregnancy and a major health issue among women of childbearing age.

Pregnancy-related LBP is defined as: 'Recurrent or continuous pain, which occurs in the low back (12th rib to the gluteal fold) for more than one week during pregnancy"; while pelvic girdle pain (PGP) is: "experienced in-between the posterior iliac crest and the gluteal fold, particularly in the vicinity of the sacroiliac joints (SIJ). The pain may radiate into the posterior thigh and can also occur in conjunction with/or separately in the symphysis pubis" (Vleeming et al, 2008: 795). In the general population, leg pain has been frequently reported as a complication of LBP resulting in a poorer long-term prognosis, including increased pain,

greater disability, poor quality of life, sleep disturbance, increased time off work, and increased use of health care resources (Hider et al, 2015; Konstantinou et al, 2015; Kongsted et al, 2012; Grotle et al, 2010). Furthermore, pain radiating below the knee is considered to be associated with nerve root involvement and has been reported to result in higher levels of pain, disability and recurrent episodes (Hider, et al. 2015, Kongsted, et al. 2012).

In the pregnant population, leg pain is common (Sabino and Graur, 2008), particularly during the third trimester (Ginsberg et al 1992). However, leg pain associated with LBP or PGP has received little attention. Sabino and Grauer (2008) reported that pregnancy-related LBP may radiate to the buttocks and posterior thighs, but usually does not extend beyond the knees. In their survey of women who had given birth within 24 to 36 hours (n=200), Fast et al (1987) reported that, of the 112 (56%) women who were experiencing pregnancy-related LBP (PRLBP), 51 (45.5%) women indicated that the pain had radiated into their buttocks and thighs, with half of these women reporting pain referred into both legs.

Sturesson et al (1997) noted that 36% (n=44) of pregnant women with posterior PGP reported the experience of a 'catching' sensation of the leg during walking and also described various pain sensations in their legs and feet. Aside from these early studies, the involvement and extent of leg pain associated with LBP and/or PGP during pregnancy has not been widely investigated. The aim of this study was to generate a demographic profile of a national voluntary sample of women who had recently given birth, including their typical physical activity behaviours, experiences of, and treatment for, LBP and/or PGP. This paper focuses on the proportion of respondents who were affected by LBP and/or PGP.

Materials and methods

Questionnaire design
A focused literature search indicated that there were no comparable survey instruments available to investigate the areas of interest to this study. Therefore, an online cross-sectional questionnaire was developed by a multidisciplinary team of health care researchers with experience of developing and analysing online surveys, whose members were a physiotherapist specialising in low back pain, a midwife, two health scientists and a statistician. In an attempt to limit any ambiguity experienced by survey respondents, the instrument defined low back pain as 'any symptoms (e.g. pain, numbness, pins and needles etc.) felt in the area between your lowest ribs and your buttocks', and pelvic pain as 'any symptoms (e.g. pain, numbness, pins and needles etc.) felt in the pelvis'.

To mitigate the influence of recall bias, while still enabling information to be collected about women's experiences of LBP and/or PGP after giving birth, the research team specified a maximum reporting frame of two years after birth. Additional inclusion criteria included women who were not currently pregnant, were resident in the UK and were fluent in the English language. The questionnaire was reviewed by a statistician to ensure

that the question format was appropriate to generate meaningful quantitative data of specific relevance to the aim of the study.

Questionnaire
The questionnaire was developed using Qualtrics software and hosted on Ulster University's health sciences website, and the Doctoral Midwifery Research Society website. Qualtrics software allows filters to be applied throughout the questionnaire, based on the preceding survey question responses to ensure no irrelevant questions appear. In addition, it enables results to be filtered according to those respondents who met the eligibility criteria for the study, and the export of data files directly to packages, such as Statistical Package for the Social Sciences for Windows (SPSS) and Microsoft Excel.

An online pilot study was initially undertaken with a purposive sample of volunteer mothers, health care professionals and complementary therapists (n=28), to establish the face and content validity, along with test-retest reliability of the proposed questionnaire (each participant completing the questionnaire on two occasions one week apart). Feedback on the content, wording and format of the questionnaire, information sheet and implied consent was then incorporated into the final version of the questionnaire in preparation for the main study. The final version, available between February 2012 and September 2013, included six sections: demographics, birthing history, history and treatment for LBP and/or PGP and habitual physical activity prior to, during, and after the most recent pregnancy.

A mixture of open and closed questions were used throughout, with closed questions predominating to minimize the time needed for respondents to complete the questionnaire, optimise the relevance of questions to the study aim, allow direct comparisons to be made between respondents, and facilitate a more sophisticated level of objective analysis (Hicks, 1999). This paper focuses on the data collected from women who had experienced LBP and/or PGP.

Ethical implications
Due to the exploratory nature of this survey, the investigators were aware that sample respondents could potentially divulge information for which they may require further advice and support. Similarly, respondents experiencing LBP and/or PGP may wish to seek specialist treatment, e.g. from a physiotherapist specialising in women's health. Women were provided with relevant advice and advised to contact the appropriate specialist for help. In some cases, women were directed to their General Practitioner or relevant professional websites, e.g. Royal College of Obstetricians and Gynaecologists, Chartered Society of Physiotherapy – Women's health, Stillbirth and Neonatal Death Society (SANDS).

Data analysis
Reliability analysis for the pilot data was completed by determining the Cronbach's alpha or kappa values. Descriptive statistics were presented for all respondents

Figure 1. General health profile of eligible respondents (n=161)
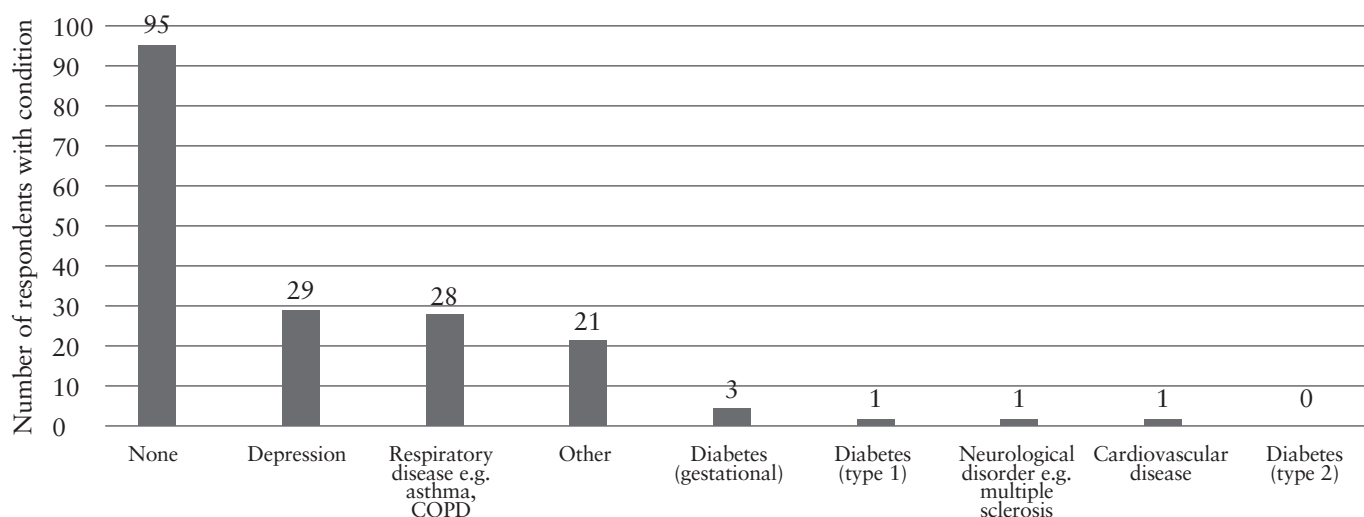
meeting the study eligibility criteria and submitting their results. The remaining statistical analyses were completed on data from respondents who had a history of LBP and/or PGP (n=110) lasting for more than one week. As data were normally distributed, parametric statistics were used, where appropriate, and the level of significance was set at p <0.001. For data collected on pain, repeated measures ANOVA was used to determine if there were significant differences between the bothersomeness and intensity of pain. Chi-square analysis was used to explore the relationship between two nominal variables. Paired samples t-tests were performed to compare LBP and PGP at each time point. All statistical tests were carried out using SPSS, Version 21.

Results

Pilot study

A total of 82% of kappa and Cronbach's alpha values were over 0.7, which suggests test-retest reliability, with 90% of values over 0.6 indicating a good agreement (Altman, 1991). Responses to other questions demonstrated moderate agreement. These questions were re-worded according to participant feedback to improve clarity. The information sheet and implied consent were also incorporated into the final version of the questionnaire in preparation for the main study.

Main study

Of 332 women who consented to participate, 58% (n=191) were eligible to take part and 176 submitted their results. Respondents were from all four UK countries; England 75% (n=144), Scotland 11% (n=21), Northern Ireland 9% (n=17), Wales 5% (n=9), with a mean age of 31 years (30.46 +/- SD 7.70). The majority were of white ethnic origin (n=165) and currently employed (n=133): occupations included, 'stay at home mum', 'HR manager', 'company director', and '(emergency) nurse'. One hundred and fourteen respondents had completed, or were currently in higher level education. The general health profile of eligible respondents is represented in Figure 1, above.

One hundred and fifty-seven respondents completed the section on 'History of LBP and/or PGP' and almost three quarters had previously experienced symptoms lasting for more than one week (n=110, 70%). Eighty-one women had experienced either LBP (n=48, 31%) or a combination of LBP and PGP (n=33, 21%) before, during or after pregnancy. Almost two thirds (64%) of women had leg-involved LBPGP, regardless of whether it began before (n=40, 25%) or during pregnancy (n=61, 39%). Of these 101 women, accompanying leg symptoms were experienced in one (n=51) or both legs (n=50).

Six women (4%) experienced PGP alone; interestingly, none of these women reported any leg symptoms. Twenty-one (13%) women experienced LBP and PGP at different times, with 13 (62%) reporting associated leg symptoms. Forty-seven women (30%) had never experienced LBPGP. Figure 2 represents the number of women reporting LBPGP symptoms at different time points.

Of those women who had ever experienced LBP (n=104), 68.3% also reported concomitant symptoms in one

Figure 2. Number of women in this study reporting symptoms of LBP and PGP (n=110)
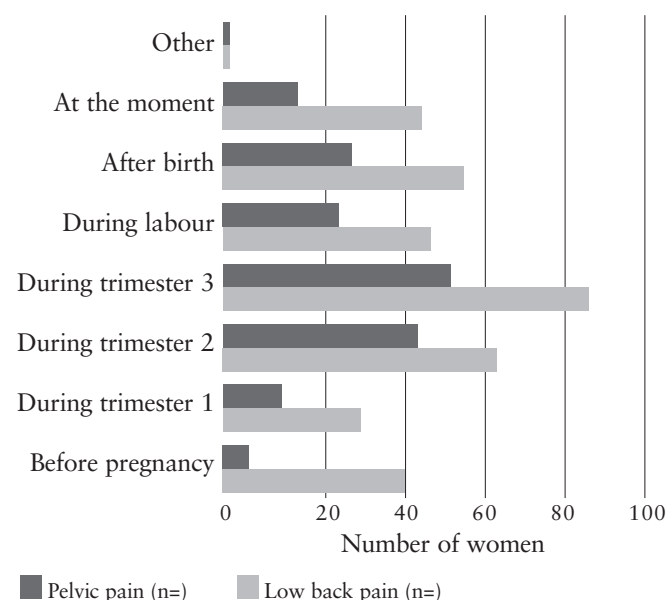
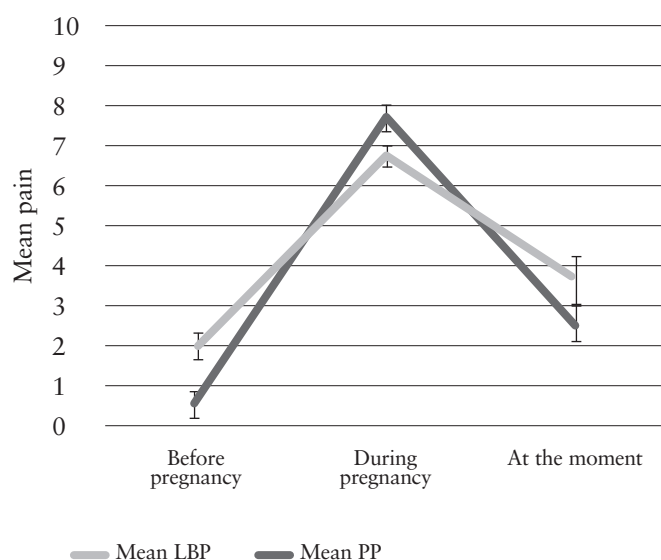**Table 1. Leg pain referral patterns for women experiencing LBP and/or PGP during pregnancy (%)**

	Low back pain (n=104)	Pelvic pain (n=59)
No leg pain	33 (31.7%)	29 (49.2%)
One leg involved	38 (36.5%)	13 (22.0%)
Two legs involved	33 (31.7%)	17 (28.8%)
Thigh	30 (28.8%)	17 (28.8%)
Knee	19 (18.3%)	9 (15.3%)
Ankle	10 (9.6%)	1 (1.7%)
Heel	3 (2.9%)	3 (5.1%)
Toes	12 (11.5%)	3 (5.1%)

Table 2. Descriptions of leg pain experienced by women experiencing LBP and/or PGP during pregnancy

	Low back pain (n=73)	Pelvic pain (n=46)
Numbness, pins and needles, tingling	37	15
Pain	28	12
Throbbing/aching	26	19
Shooting	17	8
Stabbing/sharp	14	9
Cramping/spasm	5	1
Hot, pressure, gravely, grinding, nervy	5	4
Restless/uncomfortable	2	2

(n=38, 37%) or both legs (n=33, 32%). Women with PGP (n=59) reported associated leg symptoms in one (n=13, 22%) or both (n=17, 29%) legs (Table 1). Women described a wide variety of leg pain symptoms (Table 2).

Women were asked to estimate the average intensity and bothersomeness of pain before and during their most recent pregnancy, along with pain 'at the moment', intensity and bothersomeness were measured separately and a final mean score calculated in accordance with the LBP literature (Nacir et al, 2019). Survey respondents were asked to rate on the sliding scale, with 0 being no pain, and 10 being the worst imaginable pain, how intense their LBP and PGP had been and before, during and after their most recent pregnancy. Figure 3 represents the average pain experienced by women.

One-way ANOVA revealed significant differences in the intensity and bothersomeness of pain between the three time points for both conditions and paired samples t-tests were

used to establish where those differences occurred. LBP and PGP were both significantly lower before, compared to after pregnancy (LBP t=4.064, p=0.0005 df 158; PGP t=3.995, p=0.0005 df 158). Figure 3 reflects the steep rise in pain for both conditions during pregnancy. Although PGP rose to a higher level, this difference was not statistically significant. However, postnatal LBP intensity (t=2.858, p=0.006 df 47) and bothersomeness (t=4.051, P=0.0005 df 47) was significantly higher than for PGP. Mean LBP was also higher than mean PGP after delivery (t=6.887, p=0.0005 df 158). There was a significant small correlation, corresponding to a 22% shared variance, between suffering from depression and having had LBP prior to pregnancy (Pearson's Correlation r=0.148 significant at the 0.01 level (2-tailed)).

Discussion

The findings of this study indicate that more women reported suffering from LBP than PGP before, during and after pregnancy, with both the intensity and bothersomeness being significantly higher before and after pregnancy for those with LBP. Although mean PGP rose to a higher level during pregnancy, LBP also saw a dramatic rise as pregnancy advanced, and there were no significant differences in mean pain between the two groups at this time point. This pattern of increased pain as pregnancy advances is well supported (Liddle and Pennick, 2015; Mota et al, 2015). Interestingly, the higher levels of PGP experienced during pregnancy by women in this study, is in contrast to the findings of Skaggs et al (2007). Although PGP decreased to significantly lower levels than LBP after pregnancy, women in this study still reported symptoms of LBP and/or PGP for up to two years after birth. These conditions are often deemed to be a 'normal part of pregnancy', however, their persistence has been reported for up to 10 years after delivery (Elden et al, 2016). Therefore, this strongly indicates that health care professionals should consider the potential direct and indirect cost implications for women in their most financially productive years.

Figure 3. Mean LBP and PGP experienced by women in this study (n=110) before, during and after pregnancy.

This current study's findings also suggest that the experience of PRLBP is more likely to involve leg symptoms. Sixty-eight percent of women in this study experienced leg pain, or other symptoms, associated with LBP, which is almost twice as many as that reported by Fast et al (1987) (37%). Although the women in this study used a wide variety of descriptors to explain their symptoms, in agreement with Close et al (2016), none described the sensation of the leg catching during gait, reported by Sturesson et al (1997). 'Catching' of the leg during gait is often associated with inadequate form and/or force closure of the sacroiliac joint (SIJ) (Lee, 1996; Panjabi, 1992), therefore, this may not have been a problem for women who chose to take part in this study.

Leg symptoms were most commonly described as pins and needles/numbness and throbbing that, for some travelled as far as the toes (as shown in Table 1). The following descriptions reflect how leg symptoms often resulted in functional limitations:

"Severe pain to my knee, so much so my leg would lock and I couldn't move."

"Pins and needles, loss of stability, sharp shooting pains."

"Sharp pain running down the inside of my leg that would make it difficult to stand… affected both legs."

In support, Grotle et al (2010) concluded that leg pain referred from LBP in a general population sample (n=926), and leg pain below the knee were predictors of LBP-related disability 12 months after initial LBP presentation (measured using the Roland Morris Disability Questionnaire). Konstantinou et al (2013) has also recently underlined the importance of early identification of LBP with associated leg pain, in the general population, in order to ensure effective treatment. As more than two-thirds of women in this study who experienced LBP and/or PGP also reported leg symptoms, and many women had a history of LBP before pregnancy, it would be prudent to prioritise the development of effective treatment pathways that incorporate such predictive factors already identified from studies conducted in the general population. Not only is appropriate assessment fundamental for effective LBP management in the general population, consistent terminology and classification of pregnancy-related LBP of musculoskeletal origin is paramount in order to identify possible predictors of chronicity and facilitate much needed research and treatment development in this area (Liddle and Pennick, 2015; Nacir et al, 2009). An earlier study by Sinclair et al (2014) demonstrated 64% of the sample of women who experienced pregnancy-related LBPGP were using medication to manage their pain, of which 40% were prescribed and the remainder were purchased over-the-counter. Women were self-medicating for pain management and disclosed taking a range of pain medications including paracetamol, codeine, and NSAID. This further demonstrates the need for pain management strategies.

Furthermore, in the general population depression may play a role in LBP prognosis (Pinheiro et al, 2016). In a Qatari study 13.7% of people experiencing LBP also suffered from depression (Bener, et al. 2013). In this study the findings suggest that 22% of LBP prior to pregnancy may have been associated with depression. In the pregnant population, a greater understanding of the role of psychosocial influences on pregnancy-related LBPGP is required, given the likely association with mental health problems and LBP in the general population.

There are several limitations in this study. Retrospective studies are thought to report lower levels of pregnancy related LBP and / or PGP compared with prospective studies (Perkins, et al. 1998), most likely due to issues surrounding recall of pain levels during pregnancy and the tendency for symptoms to decrease after birth. Future studies may adopt a prospective survey which may establish a more representative picture of pain patterns, descriptions and severity of symptoms. The extent of social desirability bias in participants' responses is also unknown, and must also be acknowledged as an inherent limitation in the study design. In addition, the majority of the respondents lived in England, which limits the representativeness of the sample. Furthermore, the study design may have resulted in self-selection bias and, given the relatively small numbers who were eligible, the sample may not be truly representative of women having given birth within the previous two years.

Conclusion

This is the first study to report concomitant leg symptoms with pregnancy-related LBP and/or PGP. Our findings suggest that both complaints can have a significant impact on women during their pregnancy and that LBP, in particular, is associated with leg symptoms, is more intense, and more often persists after delivery than PGP. Therefore, LBP during pregnancy, particularly when associated with leg symptoms, requires not only further investigation, but timely diagnosis and management, as is the case for those with non-specific LBP, in order to reduce the incidence of long-term pain for women and reduce the impact it has on their lives.

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Early informational support prior to recommended time points in NICE clinical guidelines: implications for pregnant women and midwives. A systematic literature review

Alison Ledward PhD, MPhil, MSc, BA.
Freelance writer, Department of Health Sciences, University of Leicester, George Davies Centre, University Road, Leicester LE1 7RH, England.
Email: alisonledward234@btinternet.com.

Abstract

Background. High quality interactions between women and midwives are known to enhance maternal autonomy and choice, may increase women's participation in decision-making and are a quality marker of their maternity care.

Aim. The aim of this review was to determine the knowledge-base about pregnant women's need for early informational support prior to recommended time points in NICE clinical guidelines.

Objective. The objective was to understand how the timing of recommendations in current guidance impact on women and midwives.

Methods. A structured systematic literature search using PRISMA guidelines was conducted. Search terms: 'women', 'midwife', 'timing of information-giving', 'early informational support', 'pregnancy', 'labour', 'birth' and 'clinical guidelines' were used separately and in combination. A systematic electronic search was carried out on CINAHL, the Cochrane library, expert document websites: the RCM, Medline and Sage journals, government websites: DH and databases for existing antenatal guidelines: NICE. Grey literature sources were searched using Google Scholar and reference lists of relevant books and theses identified. Selection criteria: the inclusion criteria were peer-reviewed research papers published in English from July 2000 to August 2018.

Findings. The search of the databases identified 143 papers. After removing duplicates, 98 were of potential interest. Following screening of the title and abstract, 63 were excluded because of lack of specificity to women's experiences. The full texts of 35 papers were read and a further 18 excluded, resulting in 17 papers for critical review. Four of these papers suggested that pregnant women wished to receive information earlier than is currently the case, but guidelines were referred to only briefly.

Three themes were identified: features of communication women value most, the content and quality of antenatal care and the importance of information-giving/ exchange between women and midwives.

Conclusion. This review's findings suggested that further research about women's need for early informational support is warranted. Based on this review's findings, implications for midwifery practice, research and education are considered.

Key words: Midwives, clinical guidelines, women's information needs, early informational support, women's participation in their care, evidence-based midwifery.

Background

The aim of information-giving during pregnancy is to prepare women for birth and motherhood (Kristjansdottir et al, 2014; NICE, 2008a).

National Institute for Health and Care Excellence (NICE) maternity care guidelines stress the need for women to be given personalised information about the risks/benefits/comparisons of treatment options. Their wider recommendations state 'Good communication between healthcare professionals and women is essential. It should be supported by evidence-based written information tailored to the needs of the individual woman' (NICE, 2008a).

There is increasing recognition about the importance of high-quality interactions between women and midwives in enhancing maternal autonomy and choice during pregnancy (Miller et al, 2016) and postpartum (Renfrew et al, 2014). It is also relevant that women's experiences about their participation in decision-making impacts on their perceptions of the quality of their care (Heatley et al, 2015).

Evidence suggests that timely informational support helps women feel prepared and confident in their transition to parenthood (McKellar et al, 2009) and improves maternal and

fetal outcomes (Shieh et al, 2010). Previous work suggested that women value information prior to the onset of labour, for example, during antenatal appointments (Broaddus and Chandrasekhar, 2011; Dyer and Hodges, 2007) and during the latent phase of labour (Carlsson et al, 2009). The work of Davey et al (2005) and Wheatley et al (2008) found that spending adequate time with professional carers and not being rushed increased women's overall ratings of their care.

In addition, studies have shown that women want to be able to trust their midwives and share decision-making about their care (Fawsitt et al, 2017; Goberna-Tricas et al, 2011). A systematic review of the evidence about shared decision-making demonstrated improved knowledge and increased perception of having made an informed decision, greater reassurance and satisfaction (Say et al, 2011). There is also evidence to suggest that if women share decision-making at a level they are comfortable with it enhances their satisfaction with maternity care (Declercq et al, 2014).

Other studies have explored pregnant women's expectations about their care: the number of visits, healthcare providers and ways in which care is organised (Vogel et al, 2013; Ayoola, 2011). The revised Adequacy of Prenatal

Care Use (APNCU) Index (Kotelchuck, 1994) accounts for initiation of care and the number of antenatal visits. Simply counting visits without evaluation of the quality of care is insufficient (Bloch et al, 2009, Alexander and Kotelchuck, 2001). Further, evidence suggested that quality of care may be more important than the actual number of visits (Ricketts et al, 2005; Walker et al, 2001).

The Content and Timing of Care in Pregnancy tool (CTP) (Beeckman et al, 2011) measures the number of visits, but also factors in the content and timing of three interventions: blood pressure recordings, blood tests and ultrasound scans. However, the CTP has limitations. It focuses on a minimum care package, regardless of the woman's parity or risk status (Beeckman et al, 2011).

Clinical guidelines set out recommendations, but their focus is on the minimum level of care that should be offered (Beeckman et al, 2017). The authors concluded that although conceptualisation of the CTP tool could be a first step in evaluating the content and quality of care, there are other pertinent aspects which reflect quality that are excluded from the CTP. Examples include information provision and informed decision-making (Beeckman et al, 2017).

With this background, it seems crucial that features of good communication to include the timing of information should be better understood. Early information-giving and greater flexibility in the interpretation and use of guidelines by midwives may help women establish a conceptual roadmap of where their care is heading, setting the groundwork for more effective discussions between women and midwives and so enhance quality care.

NICE guidelines
'NICE clinical guidelines are recommendations on how healthcare and other professionals should care for people with specific conditions. The recommendations are based on the best available evidence' (NICE, 2012). NICE guidelines are prefaced with a statement that their recommendations are not all-inclusive and should be applied as an adjunct to professional carers' clinical judgement (NICE, 2014).

Challenges facing midwives working to guidelines.
The work of Kennedy et al (2009) identified the application of guideline recommendations as challenging for midwives. In this respect, there may be tensions associated with professional carers' interpretation of their recommendations which may affect some women's care (Upshur, 2014; Chauhan et al, 2008). One such tension is the tendency by some midwives to interpret guidelines as rules (Lavender, 2010). Rigid interpretation of the guideline might influence or even directly control the course of events when some leeway would have been appropriate. Problems include midwives dismissing women's requests for information if they come at inappropriate times according to guideline recommendations (Davies and McKenzie, 2004).

Aim
The aim of this review was to determine the knowledge-base about women's need for early informational support prior to recommended time points in the NICE clinical guidelines.

Objective
The objective was to understand how the timing of recommendations in current guidance impact on women and midwives.

Methods
Literature search strategy
The guidelines according to the Preferred Items for Systematic reviews and Meta-Analysis (PRISMA) were followed to ensure rigour throughout the review process. The search strategy aimed to identify studies that explored and reported on women's information needs in relation to recommendations in guidelines.

Search terms
The search was conducted using key words of the major concepts. 'Women', 'midwife', 'timing of information-giving', 'early informational support', 'pregnancy', 'labour', 'birth' and 'clinical guidelines' were used separately and in combination.

Sources
The electronic databases searched were Cumulative Index to Nursing and Allied Health Literature (CINAHL); the Cochrane library; expert document websites: the Royal College of Midwives (RCM); Medline and Sage journals; government websites: the Department of Health (DH); and databases for existing guidelines: NICE. In order to ensure that all relevant literature was included, grey literature sources were also searched using Google Scholar and reference lists of books and theses identified.

Review selection criteria
Peer-reviewed empirical research papers published in English from July 2000 to August 2018. The literature sample reviewed was purposive, ie, work was included on the basis of its relevance to this review. The range included empirical studies, theoretical studies, policy documents, clinical guidelines and unpublished sources, such as theses.

Papers were excluded if they demonstrated insufficient links between new and existing knowledge about women's information needs and the findings/conclusions were insufficiently supported by evidence.

Quality assessment
The review's author screened titles, abstracts, read the full text articles applying the review selection criteria and appraised included papers. The assessment process was verified by a colleague independent of the review.

As part of the method, a supporting bibliographic reference (Kotelchuck, 1994) was included, ie, the standard and most used index for antenatal care utilisation (VanderWeele et al, 2009).
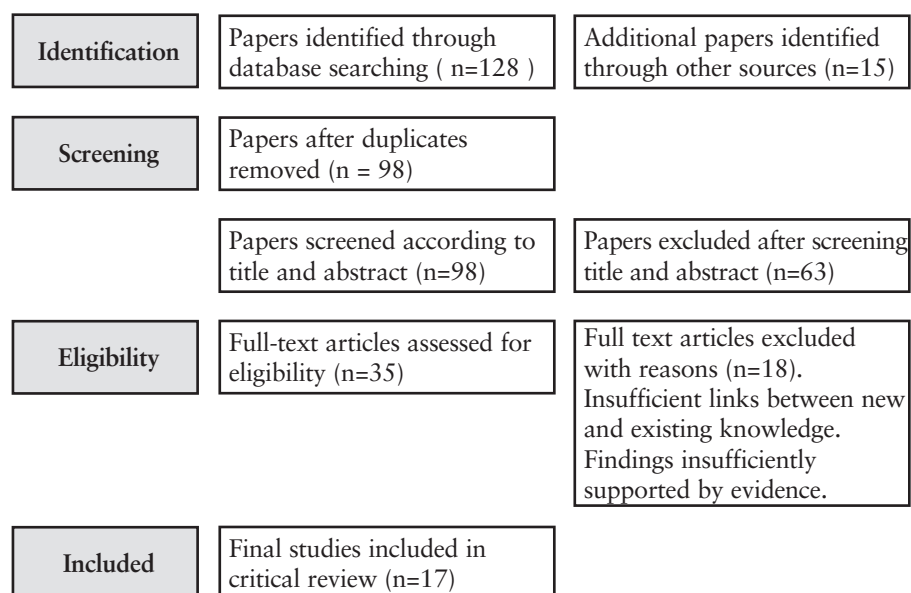
Outcomes
The initial search identified 143 papers. After removing duplicates, 98 were of potential interest. Following

Figure 1. PRISMA flow diagram, from Moher et al (2009)

Identification	Papers identified through database searching (n=128)	Additional papers identified through other sources (n=15)
Screening	Papers after duplicates removed (n = 98)	
	Papers screened according to title and abstract (n=98)	Papers excluded after screening title and abstract (n=63)
Eligibility	Full-text articles assessed for eligibility (n=35)	Full text articles excluded with reasons (n=18). Insufficient links between new and existing knowledge. Findings insufficiently supported by evidence.
Included	Final studies included in critical review (n=17)	

screening of the title and abstract, 63 were excluded because of lack of specificity to women's experiences. The full texts of 35 papers were read and a further 18 excluded because data analysis did not sufficiently address pregnant women's need for information, resulting in 17 papers for critical review. Four of these papers revealed that women wished to receive information earlier than any guideline's recommendations.

Description of included studies
Out of 17 papers, 12 used qualitative analyses. Two studies used quantitative methods and one a mixed-methods approach. Those included focused on women's experiences of information-giving, choice and decision-making. A systematic scoping review and a commentary were also included.

The study population included women from different socio-demographic groups, mixed parity and age ranges receiving standard and specialist care. Two studies included healthcare professionals' experiences.

Findings

The information retrieved was compared, synthesised and categorised into three a-priori themes, used as context for discussion of this review's findings and juxtaposed against guideline recommendations:
• Features of communication women value most.
• Content and quality of antenatal care.
• The importance of information-giving/exchange between women and midwives.

Discussion

There is a spectrum of care in which women could benefit by receiving early informational support. Although this review suggested problems with the timing of information, the concept of early informational support has not been clearly defined and little is known about its implementation.

Example one
Clinical guideline 129, Multiple pregnancy: antenatal care for twin and triplet pregnancies (NICE, 2011)
The guideline recommends that discussion should take place about intra-partum management and the timing of modes of delivery early in the third trimester (NICE, 2011).

Features of communication women value most
In accordance with current guidance, women's opportunity to engage in a meaningful discussion about the delivery of twins and triplets (which is complex) is restricted by their understanding that the mode of delivery should not be formally discussed until early in the third trimester.

This review found that women would like to be given a clearer overall picture of what to expect from their care and to understand the purpose of each appointment (Raine et al, 2010). Arguably, decision-making in pregnancy is often well-placed to include future planning, deliberation and reflection. The review revealed that features of communication women valued most were their midwives' ability to show empathy, willingness to engage in discussion and tailor information to the individual woman (Jenkins et al, 2014). Further, a caring relationship, continuity of information and shared decision-making between women and midwives enhanced maternal satisfaction with their care (Sword et al, 2012).

This review revealed the importance women attach to information being offered at the right moment for each woman (Seefat-van Teeffelen et al, 2011). Further, women wanted the option to discuss their birth preferences throughout pregnancy, not at a fixed point recommended in guidelines (Hinton et al, 2018). Early informational support would help women navigate their way through the complexities they face (Phillips et al, 2018) and provide grounds for future discussions (Aune and Moller, 2012).

Discussion points in antenatal guidelines tend to follow a linear process whereby information is provided at certain time points. There are certain merits with this approach. For example, the midwife can offer all women standard evidence-based care. However, there are instances when it may fail to respond to women's need for information that could have been a useful resource to prepare for more meaningful discussions later. As Adam (2013) said, there are occasions when issues relating to a particular future event become more pertinent: that is, individuals are concerned with what will or might become of things in the future.

In light of this review's findings, midwives should be aware that raising anew the various options at the same time that a decision point is introduced is problematic. It may not only restrict women's participation in decision-making, but

Table 1. Summary of the studies included in this review

Study	Design/methods	Sample	Outcomes
Hinton et al, 2018	7 online focus groups, 1 face-to-face focus group. Thematic analysis	69 pregnant women	Women wanted the option to consider and discuss their birth preferences throughout their pregnancy, not at a fixed point
Phillips et al, 2018	Mixed-methods, comprising cross-sectional online survey using quantitative analysis. Qualitative interviews using inductive/deductive approach based on social phenomenology	128 women in the survey, 22 interviewees planning to become pregnant, pregnant or with a child under 5 years. 7 healthcare professionals	Women with rheumatic disease reported a range of unmet needs. They and healthcare professionals suggested accessing information earlier would help women navigate the complexities they face
Ledward, 2017	Semi-structured interviews Qualitative analysis. Constructivist grounded theory	20 pregnant women	Women's accounts suggested that information –giving as it stands may provide only a small proportion of what women want at specific times
Gottfredsdottir et al, 2016	Cross-sectional using 2 questionnaires. Descriptive content statistical analysis	765 pregnant women	Time spent on information- giving correlated with more positive experiences of maternity care
Floyd et al, 2016	In-depth interviews. Grounded theory analysis	24 pregnant women	Women's accounts suggested that it was important to have information ahead of recommended times
Coxon et al, 2015	Qualitative study comprising antenatal and postnatal interviews. Narrative analysis	41 pregnant women	Women's accounts highlighted the importance of balanced information about maternity care options.
McCardle et al, 2015	Self-report survey. Descriptive statistical analysis	526 pregnant women	High quality information and good rapport between women and healthcare professionals are key features of supportive care. Information about foetal movements should be given as early as the first antenatal appointment and later reinforced.
Clark et al, 2015	Qualitative study comprising focus groups and in-depth interviews. Narrative analysis	Focus groups with pregnant women (n=24) Interviews at or around 1-3 days postnatal (n=11) Small group postnatal interviews (n=21)	Although women's expectations of their maternity care may vary, a central theme was the value women placed on high quality information
Thorstensson et al, 2015	Qualitative design. Interviews. Inductive and deductive content analysis	5 pregnant women	Women's accounts suggested the importance of meeting their individual needs with clinical and supportive knowledge
Downe et al, 2015	Systematic scoping review. Modified Framework Analysis	38 papers. 1264 women included	The review demonstrated the importance of balanced information about the risks and benefits of all birth settings to women during pregnancy. Information as it stands may only provide a fraction of what women want
Jenkins et al, 2014	In-depth semi-structured interviews. Descriptive analysis	53 pregnant women	Women expressed a wish for a caring relationship with their midwife and continuity of information
Balaam et al, 2013	Qualitative systematic review of studies. Thematic analysis	16 articles were selected, analysed and synthesised	Vulnerable women's situation can be helped by improved communication in a caring relationship with midwives
Aune and Moller, 2012	Qualitative interviews. Grounded theory analysis	10 pregnant women	Women's accounts suggested that that early information about screening tests provided grounds for future discussions
Sword et al, 2012	Qualitative descriptive approach. Semi-structured interviews. Inductive and deductive analysis	40 pregnant women. 40 healthcare professionals	Optimizing antenatal care suggested the need to focus on elements of care that promote a caring relationship between women and their professional carers. Shared decision- making is key
Seefat-van-Teeffelen et al, 2011	Qualitative design, 3 focus groups. Thematic analysis	21 pregnant women	Women's accounts suggested the importance of receiving information at the right moment for the individual
Raine et al, 2010	Qualitative design, 6 focus groups, semi-structured interviews. Thematic analysis	30 pregnant women. 15 in focus groups, 15 interviewees.	Women want healthcare professionals to convey a clear overall picture of the care women could expect to receive and the purpose of each antenatal appointment. Poor communication styles included a lack of 'woman-centred' dialogue.
Watkins and Weeks, 2009	Commentary	N/A	Many women want to participate in shared decision-making. Decision aids are important, but require support from healthcare professionals

result in information overload which may be confusing or even frightening. Entwistle and Watt (2006) claim that close attention by professional carers to the sequence of decision-making makes patient involvement more recognisable. One benefit is the 'knock forward' effect. An example is patients' involvement in problem recognition and clarification of issues that will help them better understand their options. The authors claim patients who misunderstand or are insufficiently informed may be inclined to resist involvement in their care.

Professional carers may enhance participation by seeking common ground with their patients about various points, developing an understanding of their role as potential decision-makers and building trusting relationships (Entwistle and Watt, 2006).

Example two
Clinical guideline 62, Antenatal care for uncomplicated pregnancies (NICE, 2008a)
The guideline recommends that at 34 weeks' gestation, women should receive specific information about their birth plan and help to prepare for labour and cope with pain (NICE, 2008a). This guideline was last updated in February 2019.

Research about how and whether recommendations such as these have direct clinical relevance is scarce (Dowswell et al, 2015). Different women want different things and develop their own understanding and interpretation of information. Current guidance might support or undermine a woman's participation in decisions about her care.

For example, a multigravid woman with experiential knowledge has considered and revisited different experiences and may be able to reflect on situations in which her participation was sought that enhanced her autonomy. Conversely, her views could be shaped by being unprepared during previous pregnancies and the associated negative consequences. Arguably, however, guidelines are sensitive to maternal autonomy and choice, as is evidenced in their wider recommendations 'Women should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals' (NICE, 2008a).

Content and quality of antenatal care
This review reinforced the importance of balanced, high-quality information relating to the risks and benefits of maternity care options (Clark et al, 2015; Coxon et al, 2015) and exploring women's preferences relating to their options with professional support (Watkins and Weeks, 2009). Women's accounts suggested the value of receiving information ahead of time and this being reinforced later in pregnancy (Floyd et al, 2016; McCardle et al, 2015). However, a systematic scoping review (Downe et al, 2015) found that routine service provision may only provide a fraction of what is important to woman. This problem became particularly apparent if care focused predominantly on clinical aspects and did not sufficiently incorporate women's expectations and wishes. In this respect, Gottfredsdottir et al (2016) found that time spent on quality interactions

with midwives correlated with more positive experiences for women, suggesting a link between sufficient information and feeling secure and cared for. Problems occurred when information was presented in ways that can be difficult for some women to understand and retain, and uncertainties about where to seek advice should unforeseen problems occur. Further problems included a lack of 'women-centred' dialogue during information-giving and when there were potential problems with the pregnancy (Balaam et al, 2013; Raine et al, 2010).

In light of this review's findings, it may help if midwives explore earlier in pregnancy each woman's particular wishes, based on an understanding that her clinical condition may change. This would help midwives to better understand the various compelling influences in women's lives, for example, personal contexts (Symon et al, 2018).

The midwife should preface the discussion by indicating the available options, followed by a skilful dialogue which clearly separates options from decision points. If the woman expresses a particular view, care should be taken to explore its basis: for example, identifying any existing knowledge she possesses and how she perceives that knowledge will impact on her future care. This approach provides a better opportunity than is currently the case for the woman to influence the course of events in subsequent appointments. It also creates trust that the midwife knows what has happened to the pregnant woman and any significant meaning she attaches to events. Subsequent appointments might reveal the need for additional information and discussion. Early information – giving supports that process.

Example three
Clinical guideline 70, Inducing labour (NICE, 2008b)
The guideline recommends that at 38 weeks' gestation, women should receive specific information relating to options for the management of prolonged pregnancy (NICE, 2008b).

Although induction of labour is an option, it presents difficulties because women have to make decisions in a prescribed and limited-time frame. It may be that guidance relies on the consumerist assumption that women act rationally on the basis of the choice they are offered. There is greater emphasis in guidelines about offering women opportunities to make decisions and less on enabling them to do so. This is surprising, given the emphasis on maternal autonomy and choice in the academic literature (Vedam et al, 2017; Noseworthy et al , 2013), within maternity care policy Maternity Matters (DH, 2007), Better Births (NHS England, 2016) and guidelines (NICE, 2014). However, the wider recommendations in guidelines state that: 'Every opportunity should be taken to provide the woman and her partner or other family members with the information and support they need' (NICE, 2008a). Enabling women to choose places greater demands on midwives' skills and time. Stacey et al (2011) suggested that supporting patient enablement to make informed decisions could be a right step in enhancing their understanding of healthcare interventions and help them exercise their autonomy.

The work of Jay et al (2018) found that in the case of

prolonged pregnancies, information was presented as little more than a predetermined plan. Their findings concur with Thompson and Miller (2014), whose work concluded that there was little value in providing information and involving women when judged against an 'external standard' whereby women themselves did not perceive that they were involved in the decision-making process. This assumption fails to account for the complexities women might face in understanding their options.

The importance of information-giving/exchange between women and midwives

This review found that women wanted information and discussion in line with their own agendas. Ledward's (2017) qualitative study suggested that there are alternative aspects of information-giving that are important to women: that is, information as it stands may provide only a small proportion of what women want at specific times. This finding suggested a tension inherent in guidelines. Further, this review suggested that women felt more secure when midwives offered both clinical and supportive information (Thorstensson et al, 2015).

In light of this review's findings, discussion should commence with considerations shared with the woman rather than medical options. Midwives should ensure that their practice is not based on short task-orientated interactions that may overlook important contextual factors (Jenkinson et al, 2017). The point is that women might feel more empowered if they were given the information they seek according to their own timely agendas.

In order to reduce the risk of the guideline becoming a checklist, the woman and midwife should explore together the woman's vision of what might happen at certain stages in pregnancy. This should happen early in the third trimester (or at a time requested by the woman). This might help create alignment between the woman's current situation and her expectation of involvement later, should induction of labour become likely.

The way forward

This review suggested that the timing of information is not always responsive to an individual woman's needs. Recommendations in antenatal guidelines concentrate on different stages of decision-making. This raises the question whether guidelines should focus more on the timing of information. In this respect, during antenatal appointments, points raised by women relating to their future care should be acted upon more flexibly by midwives.

There should be greater emphasis on the shifting nature of decision-making, and information-giving should become more future-orientated. As Frederick (2006) argued, uncertainty about future consequences can provide good reasons to maintain continued agreement with a previous decision, defer so as to further deliberate, or sometimes choose a certain option now. However, having a say is of limited use if women lack relevant information and feel unable to have a meaningful discussion with their midwife about what is being recommended and the steps to be taken next.

Midwives' use of guidelines

The organisation of maternity care often involves several midwives (and other healthcare professionals) over a period of time. There may be over-reliance on a single appointment for the assessment of information and subsequent decision-making. However, good practice extends way beyond the present and is likely to involve a series of actions, something that current guidance does not capture. It is important that midwives utilise each appointment to best effect as part of an ongoing process (as opposed to episodic).

In light of this review's findings, there should be agreement between a woman and midwife about what will be discussed, underpinned by an understanding that the woman's clinical condition is not static and outcomes may be difficult to predict. There should follow a clearly documented plan to continue discussion at a subsequent appointment, consistent with the 'knock forward' effect (Entwistle and Watt, 2006). This could be achieved by gradual information disclosure and the woman encouraged to consider its significance during the interim. In turn, midwives should develop greater sensitivity to women's wishes to revisit/defer/expedite decisions when appropriate.

Midwives should be mindful that rigid adherence to guidelines may restrict women's choice by locking them into information at specific times, the consequences of which may be forced choices, rushed decision-making and negative effects on maternal autonomy.

Potential benefits to women

Gradual and timely delivery of information may be formative, signposting the woman to further information and increasing her scope for participation, if that is her wish. The woman and midwife's exploration of the woman's vision of what might happen at certain stages during pregnancy could help create alignment between her current situation and what may happen later.

Urgent situations

Some maternity care options fall inside different parameters. An example is emergency caesarean birth when there is unexpected disruption to the woman's sense of time. The situation is underpinned by a sense of urgency, and the time span in which to make decisions is limited. Midwives should draw upon their clinical skills and experience to pre-empt the situation. Skilful judgement would help expand the boundaries to provide appropriate information and the necessary reassurance to maximise the woman's opportunities for participation in decision-making, if that is still her wish.

Non-urgent situations

Other guidelines relate to non-urgent situations. An example is dietary/lifestyle recommendations. Midwives should be aware that much of women's thought processes and actions take place outside appointments (Kukla, 2005). In addition, not all decisions in pregnancy have a single best option. Rather, there may be several close call options that are influenced by women's preferences. Nonetheless, the midwife can still enhance opportunities for the woman's participation. Examples include seeking her views and offering appropriate support.

Implications

Practice

In light of this review's findings about information-giving, midwives should not underestimate the ways in which information may potentially create middle ground between the woman and themselves. By ensuring the woman has understood the information and its likely implications for her future care, opportunities can be created to enhance participation in decision-making. This process may disrupt the midwife's own sense of time but may be attainable by exploration of the woman's wishes. Midwives should assist the woman to triage the information, use it to think about her decisions, identify additional support she may need and consider her future plans, in a trusting relationship with midwives.

Midwives need a sense of women's connectedness between past, present and future, upon which other times are constructed and impact on their experiences. They should aim at a balance between the present and the combined effects of knowledge and future action.

Research

This review identified four studies which suggested that women wished for early informational support (Hinton et al, 2018; Phillips et al, 2018; Floyd et al, 2016; McCardle et al, 2015). However, although informative, guidelines were only referred to briefly and the studies did not account for women's needs and preferences in accordance with their recommendations. This is surprising as guidelines are key to women's care. It also places limits on what can be learned about this particular aspect of care.

In light of this review's findings, well-designed prospective and retrospective studies are required to test and refine the impact of early informational support. Studies should explore the format of information and timing of delivery that would most benefit women This would help contribute to the evidence-base required to inform midwifery practice.

Education

If there is supportive evidence that early informational support enhances the quality of women's care, it may be appropriate to offer ongoing education and training as part of professional development for current and future midwives. The focus might include comparisons of women's need for early informational support vis-a-vis the information that midwives actually give. The importance of forward planning and time allocated for clarification and discussion between women and midwives also merit inclusion.

Conclusion

This review identified several factors that impact upon women's information needs. Further, the review suggested some preliminary insights about women's need for early informational support, juxtaposed against recommendations in guidelines. However, the current knowledge-base about this element of care is limited by a lack of rigorous research.

In order to better understand the meaning of women's personal sense of future directionality that reflects their past experiences, current needs and preferences, there should be a focus on conceptual development and empirical enquiry. This should bring new insights and deepen understanding. In turn, this should help inform the approach used by midwives practising in accordance with guidelines.

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Information for authors

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News and resources

Inspire Improvement Fellowship 2020

The Inspire Improvement Fellowship is a development programme for frontline clinical nurse leaders. It is a funded programme supported by the Burdett Trust for Nursing. If you are a midwifery leader keen to expand your skills in facilitating culture change, it could be for you. The Fellowship welcomes applications from people from diverse backgrounds who are interested in person-centredness and continuous improvements in care and services. The 12-month programme starts in January 2020 and requires compulsory attendance at three two-day workshops in March, June and Sept 2020 in the West Midlands. A bursary of up to £3,000 is available. The closing date for applications is 4 November 2019. For more information, visit **fons.org/programmes/inspire-improvement**

2020/21 Harkness Fellowship

The Commonwealth Fund's Harkness Fellowships in Health Care Policy and Practice provide a unique opportunity to spend up to 12 months in the United States working with leading US health policy experts. The fellowship is open to mid-career health services researchers and practitioners from the UK who wish to conduct original research. The deadline for applications is Monday, November 11. For more information, visit **commonwealthfund. org/apply-harkness-fellowship**

King's College Hospital Nurses' League grants

The Nurses' League's Educational Grants Trust offers various awards of up to £1,500 to its members to support their professional development. To apply for an award you must be a member of the Nurses' League – a social network open to all nurses and midwives who trained at King's or its partner organisations, or anyone who has worked for at least a year as a nurse or midwife at the Trust. Application forms should be sent to the Educational Grants Trust Honorary Secretary by mid-April 2020. However, the Nurses' League will consider interim applications and payments in exceptional circumstances. For more information, visit: **kch-nursesleague.org/**

CONTENTS