

When a woman's partner fears sex in context of endo & painful intercourse

Jane Keany, Social Worker, Sex Therapist
Mphil candidate University of Sydney



Support needs of a woman with endo

- GP
 - Endometriosis clinic with a nurse practitioner, if she's lucky
 - Gynaecologist
 - Pain clinic
 - Alternative medicine support
 - Peer support group
 - Psychologist
 - Sex therapist/relationships counsellor
 - Physiotherapy
- 


#1 most important life partner

...for picking up the pieces, providing tlc, hot packs, writing notes to the boss, cooking, driving, sexual partner, helping build the family, caring for kids, reminding her she's attractive, encourager, allowing her to grieve, advocating, providing a safe haven...

(Denny, 2004a; Denny and Mann, 2007)

#1 life partner not included in biopsychosocial and multidisciplinary model

(Pluchino et al 2016; Young et al 2017)



And yet...

'clinicians ...men wouldn't want to hear about 'women's business'
inadequate training in the psychosocial - understandable
50%: unnecessary to take account of the psychosocial –
unacceptable

(Young et al 2016)



Are we letting women down by ignoring partners in the partnership?

Acknowledging impact on well partner can improve couple coping
(Brown 2007)

Partner: biggest ally or part of problem re impact of endometriosis
on a woman's sex life and relationship?
(Young et al 2017)

Painful intercourse & male partner

Dearth of research

▫Culley et al 2013a; Pluchino et al 2016

Recent exceptions

▫Fernandez et al 2006; Culley et al 2017; De Graaff et al 2016; Ameratunga 2017


Sex part of glue in happy relationships

Pressure for intercourse hallmark of 'real' sex


Taboos on serious discussion of things sexual



Alert to

- Anticipatory fear of intercourse
 - Communication difficulties & masculinity stereotyping - suppress emotions
 - Sense of loyalty to partner - suppress emotions
 - Lack of knowledge/stereotyping endo as 'women's business'
 - Prioritising his partner's needs above his own - guilt
 - Diagnosis delay - uncertainty & misunderstanding eg his partner's sexual distance
 - Gender differences in emotional response: whether he adopts a 'sorting it out' approach to his partner's pain (Culley FSA Conf Adelaide 14/10/17)
- 

Alert to

- Feelings of frustration, inadequacy, helplessness and powerlessness (Ameratunga et al 2017)
 - Depression and anxiety
 - Uncertainty re fertility – how to navigate
 - Profound loss and across multiple domains
 - Marginalised status
- 

Exploration

Lived experience:

Busy life pressure++

Be strong for B

Practical support


Research:

Male partners pick up the slack (Culley et al 2017)

Don't want to blame their partners (Culley et al 2017)

Prioritise their partner's needs (Hudson et al 2016; Culley et al 2017) & preoccupied with partner's pain (Culley et al 2015)

Think showing emotion a sign of weakness (Culley et al 2017)




Diagnosis delay

Lived experience:

Lack of education about diagnosis - does not attend partner's medical appointments

Relief at diagnosis & anger at time it took



Diagnosis delay


Research:

Despite endo symptoms cause r'ship problems, partners mostly not invited to medical consultations & yet continue to support partners/ in joint decision making about endo (Ameratunga et al 2017)


No obvious cause for symptoms/diagnosis delay can strain partner's support (Fernandez et al 2006)

Relief at diagnosis, anger at years, doctors (Ameratunga et al 2017)

Diagnosis helps couples understand the reason for symptoms (Culley et al 2013)



Are we letting women down by excluding partners from the endo world?



Painful intercourse history – part 1

Beatrice: Longstanding pain

Vaginismus

Dilation training and experimentation pleasure



Painful intercourse history – part 2

Birth trauma++

Post birth painful intercourse - Pushes through pain at times

Hope for another baby

Endo diagnosis




Painful intercourse history – part 2

Research:

Women sometimes don't tell their partners they're in pain

Common for male partners to question their own attractiveness, feel rejected, in the face of their partner continuing to not want intercourse (Jodoin et al 2008; Culley et al 2013), as one of my study participants said:

'ok well she's got something wrong with her that, obviously it's that and it's maybe it's temporary, and then you're like start questioning yourself so you think is, is it something that I've done? Is I'm, am I not as attractive to her as I used to be?'



Anticipatory fear

Repeated painful intercourse leads to association of intercourse with fear & non-consensual pain
 Interrupts sexual response cycle
 Despite pain, Bea wants to continue & Frank wants to stop
 Other times when Frank initiates, Bea says no
 Communication difficulties can ensue

Anticipatory fear ctd

Research

Women continue with intercourse despite pain – difficult choice - avoiding intercourse or enduring pain for intimacy (pers comm Lorraine Culley 2017)

Anticipatory fear (Pluchino et al 2016), affects sexual response cycle (Payne et al 2005; Thomten et al 2011; Thomten and Linton 2013)

Male partners feel guilty mentioning own needs (Brown 2007; Culley et al 2013)

Partners can get frustrated, misunderstandings over sexual pain, don't talk (Seear 2009) lead to arguments (Ferrero et al 2005; Denny & Mann 2007; Vercellini et al 2012; Fritzer et al 2013) & even relationship breakdown (Fagervold et al 2009; De Graaff et al 2013)

Study participants in their own words

'...in a relationship initially it would be that a mutual, sometimes she would want to instigate something with me and I'd instigate stuff with her. Then it became lopsided and I was the only one trying to instigate stuff with her and obviously that perpetuates the guilt ... cos you feel like you're the one trying to satiate your own guilty sexual desires on someone that's clearly in pain'

'feel bad for her and feel bad that I was, you know it's almost like survivor guilt...feeling bad you know so while I've had my fun, but you know the, the woman I love is in pain and discomfort'

'any time it's [sex] brought up she withdraws into her shell and it's me against her which is bizarre because it's me and her together'

Back to Frank

No intercourse 3/12 - scared to initiate
 Not sexual in any way & no friendly touch
 Sexual response cycle & anticipatory fear
 Erectile difficulty

Research:

Unwanted pain can interrupt partner sexual response cycle, can cause sexual dysfunction (Barlow, 1986; Janssen et al., 2000; Salemink and van Lankveld, 2006; Pluchino et al 2016)

Male partners can feel fearful initiating physical intimacy in the presence of painful intercourse (Brown 2007; Culley et al 2017)

Some couples haven't found alternatives to intercourse to express intimacy (Culley et al 2017)

Men can sexually distance themselves to avoid hurting partner in intercourse (Culley et al 2013)

‘At a time when there is no cure available for the biological, attending to the psychological and social [+ relational] may facilitate better assistance to women in the lifetime management of endometriosis’ (Young et al 2017)
