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“The Health System Just Wasn’t Built for Us:” Queer Cisgender Women and Gender-Expansive Individuals’ Strategies for Navigating Reproductive Healthcare

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Abstract

Background: The LGBTQ health disparities literature documents barriers to comprehensive and queer-inclusive care. Queer cisgender women and gender expansive individuals assigned female at birth (AFAB) experience myriad health disparities related to reproductive health, in part due to the healthcare system. However, few studies have examined how queer individuals cope with and overcome barriers to queer-competent reproductive healthcare. This study aims to understand the strategies queer cisgender women and gender expansive individuals use to meet their reproductive health needs.

Material and Methods: Investigators conducted interviews with 22 queer cisgender women and gender expansive individuals AFAB about their experiences seeking reproductive healthcare services. We used inductive coding and thematic analysis to identify themes related to meeting reproductive health and healthcare needs.

Results: Findings highlight the prevalence of negative and harmful experiences while seeking reproductive healthcare. In response to these negative experiences, individuals developed active strategies to meet their health needs, including seeking information and community, seeking alternative models of care, and managing identity disclosure. Importantly, these strategies varied in effectiveness, depending on participants’ social and economic advantage.

Conclusions: Queer individuals face numerous barriers to queer-competent reproductive healthcare when seeking reproductive health services. While queer patients are often resilient and creative, developing strategies to get their needs met, the presence of such strategies highlights the need for structural changes in the health system to better serve queer patients.

Queer cisgender women and gender expansive individuals assigned female at birth (AFAB) are more likely than their heterosexual and cisgender peers to encounter stigma and bias in health settings (Graham et al., 2011). Negative encounters are associated with a reduced likelihood of returning to care, increased mistrust of the health system, and reluctance to disclose their identity to providers, which in turn may lead to poorer health outcomes

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(Conron et al., 2010). Extant literature regarding queer cisgender women and gender expansive individuals demonstrates less frequent STI screenings, less frequent cervical cancer screenings, reduced likelihood of receiving appropriate contraceptive counseling, and lower rates of contraceptive use (Charlton et al., 2013; Everett et al., 2019; Solazzo et al., 2020; Tabaac et al., 2018). Such outcomes stem from inadequate representation in sexual education and reproductive health promotion, misinformation among providers, and stigma and discrimination in the health system. (Baker et al., 2020; Grant et al., 2010; Higgins et al., 2019; Wingo et al., 2018).

While the role of the healthcare system in contributing to health disparities for queer cisgender women and gender expansive AFAB individuals is well established, less is known about how individuals interpret and then overcome the healthcare system barriers. However, there is growing recognition that minoritized patients do not passively experience oppression, but actively resist stigma and oppression in the context of healthcare encounters (Paine, 2018; Seelman & Poteat, 2020). For example, recent evidence suggests that patients are strategic about their disclosure. Greene et al. (2019) found that in the context of contraceptive care, sexual minority women assess for the safety of disclosure and weigh the costs and benefits of disclosing their identity to their providers. Similarly, a qualitative study of transmasculine patients who had been pregnant found that patients often made a conscious choice to conceal their identity in order to avoid transphobia and stigma from their OB/GYN providers (Hoffkling et al., 2017). Other strategies used by transmasculine and non-binary adults include relying on social support, displaying persistence in navigating healthcare, and avoiding mainstream healthcare (Seelman & Poteat, 2020). While there has been attention to strategies used in healthcare in general, less attention has been paid specifically to reproductive healthcare—an area that may require unique strategies given the hetero- and cis-normative assumptions that surround it (Higgins et al., 2019; Kattari et al., 2020). To address the gaps in understanding of how queer individuals AFAB navigate reproductive health-related care, this study aims to understand the strategies queer individuals AFAB used to meet their reproductive health needs. This study advances our understanding of queer and gender expansive AFAB patients as active navigators of reproductive healthcare.

Methods and Materials

Overview

Data for the current study come from a larger modified grounded theory study designed to understand the role of sexual identity in pregnancy desires and decisions among individuals assigned female at birth who identified as queer, and the role of health and social services in shaping pregnancy decisions and experiences (Carpenter & Niesen, 2020). Individuals were eligible to participate if they were between 18 and 40 years old, were assigned female at birth and identify as queer (i.e., a non-heterosexual identity), and planned on trying to get pregnant in the next five years or had already been pregnant. Both queer cisgender women and gender expansive individuals AFAB were included in the sample. Sexual identity and gender identity are separate, yet intertwined and fluid identities for many individuals (Diamond et al., 2017; Scheffey et al., 2019). Importantly, some participants indicated that

they identified as women in the initial screening questionnaire, but indicated they were non binary or genderqueer during the interview. To respect and include the identities of all participants, we describe the sample as queer cisgender women and gender expansive individuals AFAB (hereafter, queer individuals AFAB) (Jahn et al., 2019). Participants were recruited via targeted posting on social media, such as posts in LGBTQ+ social groups. Online recruitment methods secured participants from both the PI's local area and across the U.S. Interested participants filled out a screening survey with demographic, location, and contact information, which assisted in purposive sampling. Interested participants with multiple marginalized identities—namely BIPOC, people with low incomes, and those from rural areas—were prioritized in scheduling.

Data Collection

Interviews took place via Zoom or in person for local participants, per their preference. Interviewees were compensated with a \$30.00 Amazon gift card for participating in an initial interview and \$15.00 for participating in a follow-up interview. The PI, a trained qualitative interviewer with significant prior experience with primary qualitative data collection, conducted all interviews using a semi-structured interview guide that included questions on queer identity, pregnancy plans, past pregnancies, and factors informing pregnancy desires or experiences. A preliminary interview guide was piloted with 3 individuals who fit the study criteria and held expertise in LGBTQ+ health. Feedback from the pilot interviews was used to refine the interview guide. At the end of the initial interview, participants could opt in to a brief follow-up interview. Of the 22 total participants, 13 participants participated in a follow-up interview. The follow-up interviews allowed participants to reflect on the interview experience and share insights or responses that had emerged since the first interview. All interviews were audio-recorded and transcribed verbatim by a professional transcription service and de-identified by the study team.

Data Analysis

From the larger study, investigators identified navigating healthcare as a key barrier to participants exercising their parenting and pregnancy desires. This element became the basis for the current analysis. The current analysis, lead by the PI and a team of three research assistants trained in qualitative coding, was informed by Braun and Clarke's thematic analysis techniques (Braun & Clarke, 2006). The coding team engaged in a targeted coding process of transcripts describing in-depth experiences in the health system, then organized common experiences and responses to experiences. All transcripts were coded by the PI and one other member of the coding team. We held weekly coding meetings to resolve discrepancies and ensure consistent use of the codes. All coding was done using NVivo 12 (QSR, 2017). Through analytic memo-writing and discussions among the research team, we refined and clarified new-subthemes, which form the basis of the results presented (Birks et al., 2008). This study was approved by the University of Wisconsin-Madison Institutional Review Board.

Sample

The majority of the 22 participants were in their 20s (n=12), identified as cisgender women (n=15), identified as White (n=15), and had a college degree or higher (n=19). Participant

demographic characteristics are displayed in Table 1. Participant demographics attached to quotes are self-described and pseudonyms and pronouns were indicated by the participants.

Results

Results detail the strategies that participants developed in response to negative experiences and barriers to inclusive, queer-competent healthcare. Nearly every participant reported a negative encounter while seeking reproductive healthcare services (e.g., fertility treatments, contraception, abortion, or prenatal care). Despite encountering these negative experiences and barriers to queer-competent care, participants displayed resilience and creativity by developing strategies to get their reproductive health needs met. These strategies include: seeking information and community, seeking alternative care, and managing identity disclosure.

Strategy One: Becoming Experts in their Own Care and Creating Community

Participants noted a profound lack of information about queer-specific reproductive health and faced multiple gaps in access to relevant health information. In response, participants sought information from a variety of sources, both to assist them in becoming better advocates for their health needs and to combat feelings of isolation. For example, Zoey (they/them, queer, White, 25) sought information about queer individuals seeking an abortion and said:

I feel like it can feel really isolating...When the internet doesn't have answers for you, that's when you know you are in some deep territory.

Participants filled their information gaps and sought to become “experts” in their healthcare and health needs. Robyn (she/her, lesbian, Latina, 29), for example, reported spending time seeking information from “online, books, YouTube, other people’s experiences yeah... everywhere...now I’m always educating people because nobody has done the research that I have.” Participants commented about the vast information networks, fueled by people like Robyn, who shared their research and experience. Given the additional concerns around queer pregnancy, participants found themselves in need of specific information that clinics could not provide them. Raven (she/her, queer/lesbian, White, 34) described the informal network:

There’s no education...we, as a community, figure it out in our own right, through talking to each other [online]. It’s not like when you go to a fertility clinic, they have some sort of workshop where they explain all of that to you.

In filling their information gaps, participants found community in other queer people seeking healthcare, especially those who were trying to get pregnant. This helped participants both practically, in finding the information they needed, and emotionally by alleviating feelings of isolation. Ava (she/her, queer bisexual, Native American/Latina, 28) conveyed that “I have found that I’ve been seeking out community more now... I don’t think it makes us feel more ready, but it makes us feel like we’re not the first to do what we’re doing.” Online communities played an important role in filling information gaps, sharing knowledge, and providing support.

Strategy Two: Alternative Care and Demedicalizing Care

Participants described seeking alternative care to increase the likelihood of access to queer-informed providers and to gain control over their care. Many participants described intentionally seeking queer providers (or known queer-friendly providers) and seeking care outside the mainstream healthcare system, including homebirth midwives and doulas, for both pregnancy and abortion care.

Seeking care from providers who are known to be queer-friendly or are queer themselves gave participants a sense of comfort and safety. For example, Ray (They/them, queer, White, 30) talked about the benefits of “shared understanding” because queer providers have a sense of the “unspoken norms and assumptions [within the queer community] that allow you to get better care.” Participants intentionally chose providers to increase the likelihood of getting the care they needed.

Others viewed their choice of providers as a way to have control over their care. As one example, Ava’s (she/her, queer bisexual, Native American/Latina, 28) primary care physician (PCP) wanted to refer her for infertility testing. Instead, she chose to start seeing a midwife who “starts with the mindset that [I am] capable of getting pregnant, and it’s a normal thing for your body to do.” By choosing a midwife, Ava said she and her wife were “taking a little bit of power back in the situation” by resisting her PCP’s recommendations and seeing a provider who was more in line with her values.

Relatedly, participants were interested in demedicalizing the process of getting pregnant, both for emotional and logistical reasons. Participants sought clinics and providers that would facilitate this preference. Amber (she/her, queer lesbian, multi-racial, 28) and her wife intentionally sought a midwife who would allow them to do intrauterine inseminations (IUIs) at home, as a way to involve her wife, and to “be in your own home, in your own bed.” Ava and Amber’s preferences represent a desire to have more control and comfort during an otherwise stressful and overly-medicalized process.

Strategy Three: Managing Gender Identity and Sexual Orientation Disclosure

While the previous two strategies reflected participants’ choice about how and where to seek information and care, the final strategy reflected an approach to interacting with providers. Disclosure management happened in two ways: 1) allowing providers to make assumptions or simply not disclosing queer identity and 2) intentionally hiding queer identity. Disclosure management stemmed from a fear of discrimination or bias, emotional self-protection, and the desire to get the healthcare they need.

As Sylvia (she/her, queer, bisexual, White, 24) said: “coming out [to a provider] I’m just exposing myself to more stigma and discrimination.” Importantly, participants were in different places regarding disclosure, both in and out of the healthcare system. For example, Bella (She/her, bisexual, White, 27) was not out to many people in her life (“I’ve always hid my sexuality, especially when I go to the doctor...because I’d be judged”). Bella lived in a small rural town and described her provider as “very conservative.” Bella highlights the ways that discrimination and queer-phobia more broadly shape expectations about

healthcare. Because she experiences discrimination in her everyday life, she expects that to translate into her healthcare.

Beyond protecting themselves from discrimination or bias from providers, participants also made choices about identity disclosure to protect their emotional wellbeing and mental health. For example, Jay (they/them, pansexual, White, 27) said that often it is “just easier to let [providers] make assumptions,” meaning that it was less emotionally taxing for them. Jay went on to say that they would rather not disclose their identity than disclose it and not have the provider follow up, recalling a time recently where they disclosed their identity on intake paperwork. Despite Jay disclosing their identity on the form, the provider did not acknowledge the disclosure or signal that she was using it in her approach to care, which Jay viewed as more harmful than if the provider had not asked. Jay demonstrates that while creating space for disclosure may be important, a lack of follow up or inability to respond may also be damaging.

Similarly, Alex (they/them, pansexual, White, 26) saw not disclosing their identity as a way to protect themselves. During their experience getting an abortion, they said: “I just ignore that part of my identity for the time it took to take care of [my abortion].” Alex’s most pressing concern was getting an abortion, so they were less concerned with identity-affirming care in the moment. However, upon reflection, Alex attributed struggling emotionally post-abortion to the fact that they did not receive queer-informed or affirming care. “I feel like there was a lot of dissociation related to not being heard and feeling the system wasn’t seeing me.” While not disclosing their identity was helpful in the short term, the lack of affirming care had long-term consequences. Of note, passive disclosure was particularly employed by participants who were not cisgender. For example, Ray, hypothesized that they might just “drop the gender stuff” if it meant they could receive the care they needed.

Beyond allowing providers to assume they were heterosexual and cisgender, participants often felt the need to lie if they were asked how they identified. For example, Adrienne (she/her, queer, White, 27) said that she would often lie about her identity and her behavior to her providers:

I lie to most of my medical providers if I think that I need to get the type of medical care that I need...I will really play up my white, straight, middle-class persona...because it feels like I have to in order to get them to take me seriously.

Adrienne’s quote highlights that she views lying as an act of self-advocacy, as she did not believe she could get the healthcare she needed if she did not lie. However, she sees this as problematic:

It is messed up that I’m not honest with my own doctors... I just felt like it wasn’t an option if I wanted to get the care I wanted. Even though I was seeking reproductive health, I was downplaying the fact that I’m sexually active, and not disclosing that I was bi, not disclosing that I was poly, not disclosing that I had had an abortion.

Perceiving providers as queerphobic or sex-negative prevented participants from accessing comprehensive reproductive healthcare, but disclosure management was an important strategy that participants developed to overcome barriers and meet their reproductive health goals.

In contrast, some participants felt safe to disclose their identity. As Annie (she/her, queer, White, 36) stated: “In terms of gender and sexuality for White people, it’s very progressive.... I was like, it’s going to be okay with me and my partner.” Participants who saw queer providers also felt safe and comfortable disclosing their identity. As mentioned in the second strategy, seeking alternative providers was a way to ensure participants could receive queer-competent care. Given the “shared understanding” that queer providers offered their patients, participants often felt the trust and comfort required for identity disclosure.

Strategies in the Context of Systemic Barriers

Importantly, the strategies discussed above were more successful for some participants than others and social positioning and access to resources determined both the availability and success of strategic navigation of healthcare. For example, many participants commented that they *wished* they could have sought alternative care but were unable to seek out providers who met their preferences due to geographic, insurance, or cost barriers. For example, Gail (she/her, pansexual, Biracial, 32) lives in a rural town and is unsure if she will try to get pregnant while living there: “If I lived in a more blue state, I feel like the options would be broader... It wouldn’t be a roll of the dice...how are we going to be treated?” Gail’s options for providers are already limited by geography, and even more so by trying to find a queer-friendly provider. Similarly, both Raven and Robyn said they chose the fertility clinics they did because of cost. Without insurance coverage, they had to choose the affordable option, rather than the clinic they thought would provide the best care. Raven described her experience with the clinic as “uncomfortable, insensitive, and lacking awareness about [queer patients].” Robyn described her clinic as “a factory assembly line.” Financial circumstances and lack of insurance coverage often constrained choices.

Disclosure management was more possible for some participants than others. Participants who mentioned not disclosing their identity, allowing providers to make assumptions, or lying about their identity were able to do so because they “passed” as heterosexual and cisgender. Maggie (she/her, queer, White, 26) described effortlessly passing in health settings: “I think [providers] just go ‘she’s probably a straight woman.’ So, it’s not a conversation that I would plan on engaging with the doctors.” While most participants described the ability to “pass” if necessary, they also recognized their “passing privilege” (Amber).

Further, participants who felt most comfortable disclosing were located in more liberal areas of the United States or had more choices in terms of providers. In contrast to Annie, who described her city as progressive, Bella lived in a small, conservative town, with only one provider within driving distance. The lack of alternatives compounded Bella’s fear of discrimination. Geographic, cost, and insurance barriers related to provider availability allow more economically and socially privileged individuals to access more inclusive and

appropriate care and highlight systematic barriers that are easier for some individuals to overcome than others.

While participants described the strategies that they used to get the reproductive healthcare that they needed, it was apparent to them that these strategies were in response to a system that was not inclusive of queer patients. Navigating this system took a toll on emotional wellbeing. Jacqueline commented that “I think how complicated the strategies can get... Having to navigate those things can be overwhelming.” Adrienne vocalized how problematic it was that they felt lying to their providers was their only avenue to proper healthcare. There was a recognition among participants about the structural barriers to queer-competent healthcare, as exemplified by Ray: “just the way that large systems try and care for people leave most people out...[queer people] just have to work in a framework that isn’t for us.” Further, these systematic barriers to queer inclusion can be more easily overcome by some individuals than others, leaving disparate experiences for queer patients dependent on access to resources and other elements of social privilege.

Discussion

This study documented the strategies that queer cisgender women and gender expansive individuals develop to meet their reproductive healthcare needs in the face of the many barriers they report. In line with previous studies focused broadly on LGBTQ+ health that report patient navigation of bias, stigma, misinformation, and improper healthcare, this study expands these navigation strategies into reproductive healthcare contexts (Conron et al., 2010; Graham et al., 2011; Paine, 2018; Seelman & Poteat, 2020). Queer patients have developed a variety of approaches, including seeking information and community, seeking care in alternative settings, and managing identity disclosure. Importantly, this study highlights the ways in which some individuals have more ability to overcome systemic barriers through the use of these strategies than others.

Findings from this study are consistent with previous studies that identified managing disclosure as essential processes for queer individuals seeking healthcare more generally. Given efforts to collect SOGI (sexual orientation and gender identity) information on electronic medical records, it is crucial to see disclosure as a conscious choice made by patients, depending on both their previous healthcare experiences and the information they have gathered about the provider (Cahill & Makadon, 2014; Greene et al., 2019). Findings also highlight that an individual’s decision not to disclose their identity may be an attempt at emotional self-preservation, as in the case of Alex who believed it was easier to cut themselves off from their identity, or a strategic calculation about how to get the care they need, as in the case of Adrienne who would “play up [her] White, straight middle-class persona.” Reproductive healthcare settings must create an environment where gender identity and sexual orientation disclosure is both comfortable and safe. However, care providers should not view non-disclosure as non-compliance, but rather a display of resilience and strategy developed as a response to negative experiences or fear of discrimination (Asakura, 2017).

This study also expands on previous literature by emphasizing additional strategies queer patients use in the context of reproductive healthcare outside of disclosure management. Becoming “experts” in their own health needs was one strategy patients developed. Importantly, for many, attempts to become experts in their health needs stemmed from an inherent distrust of providers and the health system. This is in line with other studies that found nearly one-fourth of transgender and non-binary adults had to educate their providers to receive appropriate care and that many OB/GYNs felt unprepared to provide care to LGBTQ+ patients (James et al., 2016; Mehta et al., 2018). Further, also documented in studies about health care broadly, we see the ways that queer individuals seek support outside the health system to become more effective advocates and consumers of reproductive healthcare (Seelman & Poteat, 2020). By sharing their experiences, joining online communities, and crowdsourcing information, participants felt less isolated and were able to make more informed choices about their care. The other strategy, seeking queer providers or care from alternative sources, did alleviate many of the concerns and negative experiences participants described. However, this strategy should be interpreted in context, as many participants did not have access to alternative providers given their income, insurance coverage, or geographic location.

While this study advances our understanding of how queer patients navigate reproductive healthcare, a few limitations should be noted. First, while 60% of participants participated in follow up interviews, those lost to follow up could not be asked about emerging themes or confirm the researchers’ interpretations. Interviews focused broadly on the experiences with reproductive healthcare and did not distinguish between settings or types of providers. Future research should explicitly focus on diverse care contexts and diverse care providers, including OB/GYNs, midwives, and other reproductive health providers. The sample was mostly white and mostly well-educated. While this did not always translate to economic stability, as eight participants described themselves as lower-middle class or working poor, this was a sample with relative privilege. Given additional barriers to healthcare for racially minoritized and low-income individuals, it is possible that these results do not capture the experiences and strategies of more marginalized individuals or multiply marginalized individuals, such as queer BIPOC or low-income individuals (Agénor, 2019; Reed et al., 2011). Future research should include explicit attention to how experiences of racism or xenophobia intersect with homophobia and cis sexism, especially in the context of reproductive healthcare, given the alarming disparities and bias that exists for Black, Latina, and Native American women in the United States (Petersen et al., 2019; Wallace et al., 2017). Finally, while the sample included individuals who were assigned female at birth but did not identify as women, the sample was not inclusive of transmasculine individuals or trans men. Research should dedicate future studies to the unique experiences of gender expansive, including transmasculine, individuals.

Implications for Policy/ Practice

The strategies identified in this study suggest several intervention points for improving queer-competent reproductive healthcare. Per strategy one, reproductive healthcare could be improved for queer cis women and gender expansive individuals by ensuring all clinicians and clinical staff are prepared to care for their queer and gender expansive patients

appropriately so that patients do not bear the burden of educating their providers and to eliminate clinician-level biases (Mehta et al., 2018). Per strategy two, policies and programs that promote access to affirming and affordable clinics and providers—including doulas and homebirth midwives—would help ensure queer patients have access to reproductive healthcare providers who reflect their needs and health goals. Participants also felt more comfortable with providers who shared their identity, so increasing LGBTQ+-identified reproductive healthcare providers may also improve care. Per strategy three, clinics and providers must enact policies, procedures, and trainings that foster a safe environment for identity disclosure to providers (Cahill & Makadon, 2014; Klein et al., 2018). Furthermore, providers must receive proper training in how to respond when patients disclose their sexual or gender identity and how to follow up on disclosure respectfully. Because disclosure is a strategic decision, and safety is not guaranteed, providers must respect patients' right to make the disclosure decisions most comfortable to them, including whether or not to disclose their identity, when to disclose, and to whom they disclose.

Collectively, The presence of complex and varied strategies identified in this study demonstrate the underlying structural barriers in the healthcare system that leave queer and gender expansive patients distrustful of and harmed by reproductive healthcare (Poteat et al., 2013; Seelman & Poteat, 2020; Wingo et al., 2018). Likely, systematic bias and discrimination will persist until there are structural-level changes, including awareness of structural barriers, improved medical education, and equitable access to care, over individual-level interventions (Donald et al., 2017). This study emphasizes the importance of promoting equitable, queer-competent reproductive health care, regardless of geographic location or insurance coverage. Findings from this study also underscore the urgent need to address queerphobia and systematic barriers to LGBTQ+ equity, both in and out of the health system, to truly address the persistent disparities in queer cisgender women and gender expansive individuals' reproductive healthcare outcomes (Donald et al., 2017; Downey & Gomez, 2018; Meyer, 2016).

Conclusions

Queer individuals AFAB face numerous barriers to queer-competent healthcare when seeking reproductive health services. Study participants demonstrated creativity and resilience in developing strategies to get their needs met, including seeking information and community, seeking alternative care, and managing identity disclosure. The presence of such strategies highlights the need for structural changes in the health system to better serve LGBTQ+ patients.

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Table 1:

Participant Demographics

Demographic Characteristics N=22			
Age Range		Race/ethnicity	
20–24	3	White	15
25–29	9	Mixed race	3
30–34	4	Latina	2
35–40	6	Native American	2
Gender Identity		Highest Education	
Woman/cis woman	15	High school	3
Non-binary	3	Bachelor's degree	13
Genderqueer	2	Graduate/professional degree	6
Other ¹	2		
Sexual Identity		Previous Pregnancies	
Queer	5	None	7
Bisexual	3	1	12
Lesbian	2	2	1
Pansexual	3	3+	2
Queer + another identity (bisexual or pansexual)	9		
Previous abortion experience	10	Geographic Location¹	
		Urban (large)	8
		Urban (midsize)	6
		Urban (small)	1
		Suburban	2
		Rural	5

¹Based on CDC/NCHS city size population thresholds (Ingram & Franco, 2014)