2 What is worse: stool or urinary incontinence?
3 How we define urologic continence?
   Are the definitions of continence congruent between
   patient/family/physician perspective

Outcomes:
1. Assess the impact of stool versus urinary incontinence on the Quality of Life
   (QoL) in individuals with spina bifida
2. Definition of differences in perception of incontinence between affected
   individuals and health care professionals

Clinical Questions:
1. Are individuals with spina bifida more concerned about urinary or stool
   continence?
2. How much does stool incontinence influence the QoL of affected individuals?
3. What are the differences in defining continence between patients, their care
   takers and health care professionals?
4. How does health care perception of incontinence influence their counseling of
   affected individuals?
5. How much intervention and changes in lifestyle are individuals with incontinence
   willing to undertake in order to achieve continence?

Research Gaps:
1. Influence of mental development on urinary and stool continence
2. Many questionnaires are created by different groups but no universal accepted
   one.
3. Little to no literature concerning perception differences between health care
   providers and affected individuals
Available information from the literature:

Clinical Question 1+2:

1. Are individuals with spina bifida more concerned about urinary or stool continence?
2. How much does stool incontinence influence the QoL of affected individuals?

Most authors report a positive effect of continence on the QoL. However it is most the time not statistically significant. Surgical or conservative procedures are viewed positive (if they work). Age and maturity appear to play an important role as does gender with females being more aware. Bowel continence appears to be more important than urinary incontinence also again not really statistically significant. QoL in general appear to be significantly lower than in the general population. Adult women have significantly lower scores than men, and adolescent females have significantly lower scores for psychological well being but it is difficult to figure out how much continence plays into this. Experiences of the children and parents range from minimal impact of incontinence on their day-to-day living to significant social isolation and rejection. The stigma of incontinence is often apparent. Children and youth who are able to control their bladder with minimal accidents have greater independence and more opportunities for social participation. Additional problems arise from difficulty understanding the questionnaires and the need for help. Also patients with shunts appear to care less. Caregivers are more interested in continence and fecal continence appears to be more important than urinary. The literature is pretty repetitive and there is often not much difference between the manuscripts.

Clinical Question 3-5:

1. What are the differences in defining continence between patients, their care takers and health care professionals?
2. How does health care perception of incontinence influence their counseling of affected individuals?
3. How much intervention and changes in lifestyle are individuals with incontinence willing to undertake in order to achieve continence?

Searched for literature with all possible search phrases and did not find literature concerning if health care provider and affected individuals view incontinence different. There are papers that somewhat address if they would do surgery again but not really
how much change and surgery the patients are willing to undergo for change in continence status.

**Literature:**

1. *Bowel Management and Quality of Life in Children With Spina Bifida in South Korea.* Choi EK, Im YJ, Han SW. GastroenterolNurs. 2015 Nov 10. [Epub ahead of print]