

Patient and Family Perspectives in Spinal Dysraphism: A Mixed Methods Study

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Purpose

Spinal dysraphism describes a spectrum of conditions resulting from aberrant neural tube closure during the first trimester of foetal development. Consequent neurological deficits may lead to a myriad of musculoskeletal abnormalities amenable to orthopaedic intervention. To date, thematic analysis has not been used to evaluate the impact of these conditions on patients and their families. This study sought to evaluate this impact.

Methods

A mixed methods study was designed and employed. Free text questionnaires/interviews were collected from parents. Quantitative questionnaires were collected from children using an emoji response system. These assessed contentedness in activities of daily living. Qualitative data were analysed via thematic analysis. Descriptive statistics were applied to the quantitative data. Both arms were subsequently triangulated.

Results

32 responses (13 patients and 19 carers) were collected and analysed. The median age of patients was 10 years (IQR = 3). The gender distribution was 7 boys and 6 girls.

Three key themes emerged; independence, mental health, and family impact (Figure 1). Families expressed limitations on the independence of their children. The domains of these restrictions were reflected through the subthemes of self-care and accessibility. Likewise, the impact on children's mental health was expressed through the domains of anxiety and self-awareness. Finally, the theme of family impact was reflected through the subthemes of time and planning restrictions, and sibling impact.

Quantitative data corroborated these themes well. A minority of respondents (41.7%, n=5, Figure 2) reported contentedness when asked to consider the statement 'I can do most of my daily routine without assistance'. Likewise, 41.7% (n=5, Figure 2) were content when asked 'I can dress myself'. Regarding participation in activities with friends, a minority of patients (30.8%, n=4, Figure 2) reported contentedness in response to 'I can participate in all the activities my friends do'. A total of 5 patients (45.5%, Figure 2) responded with a happy emoji to 'I have no limitations when I am at school'.

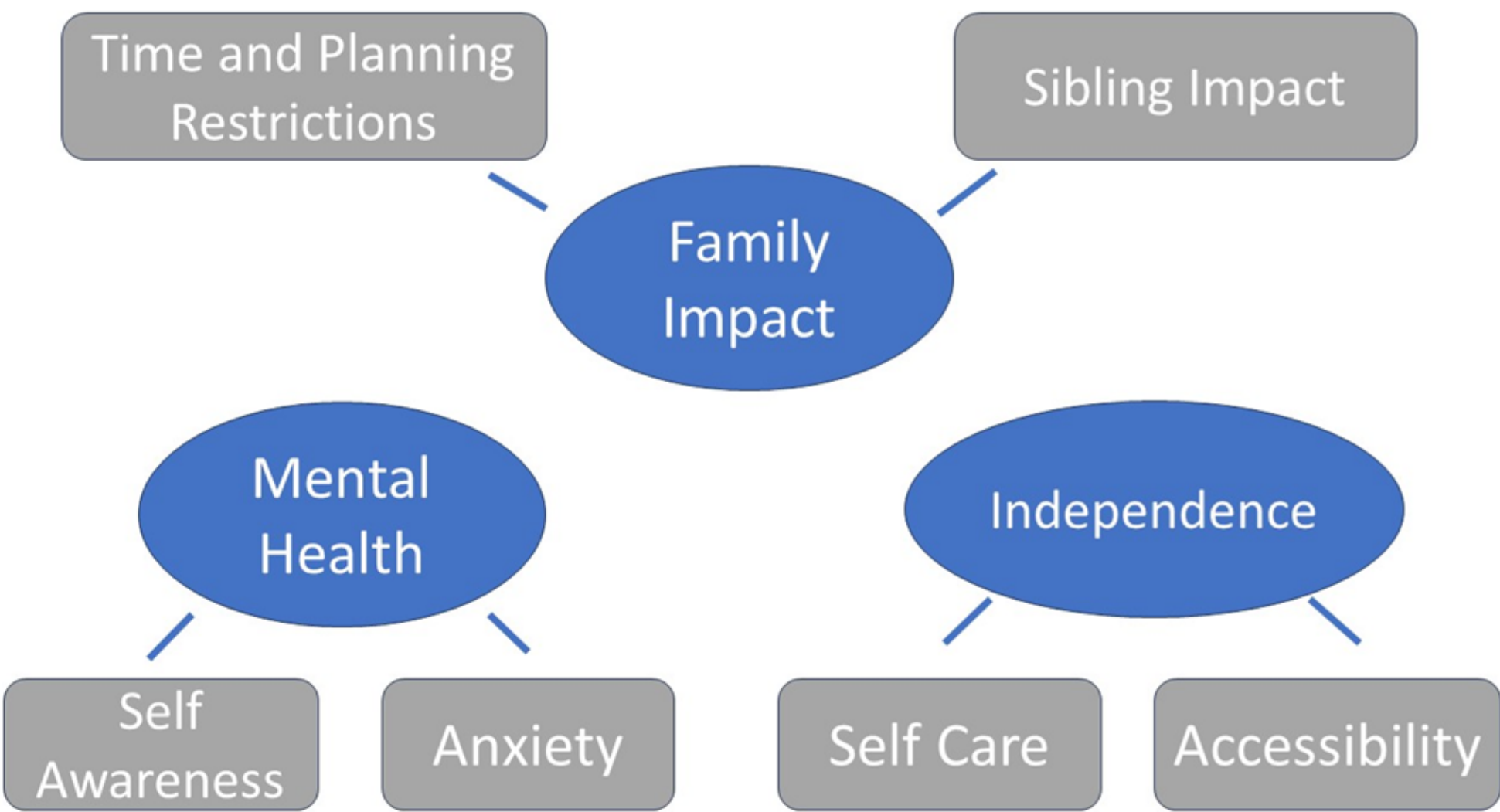


Figure 1

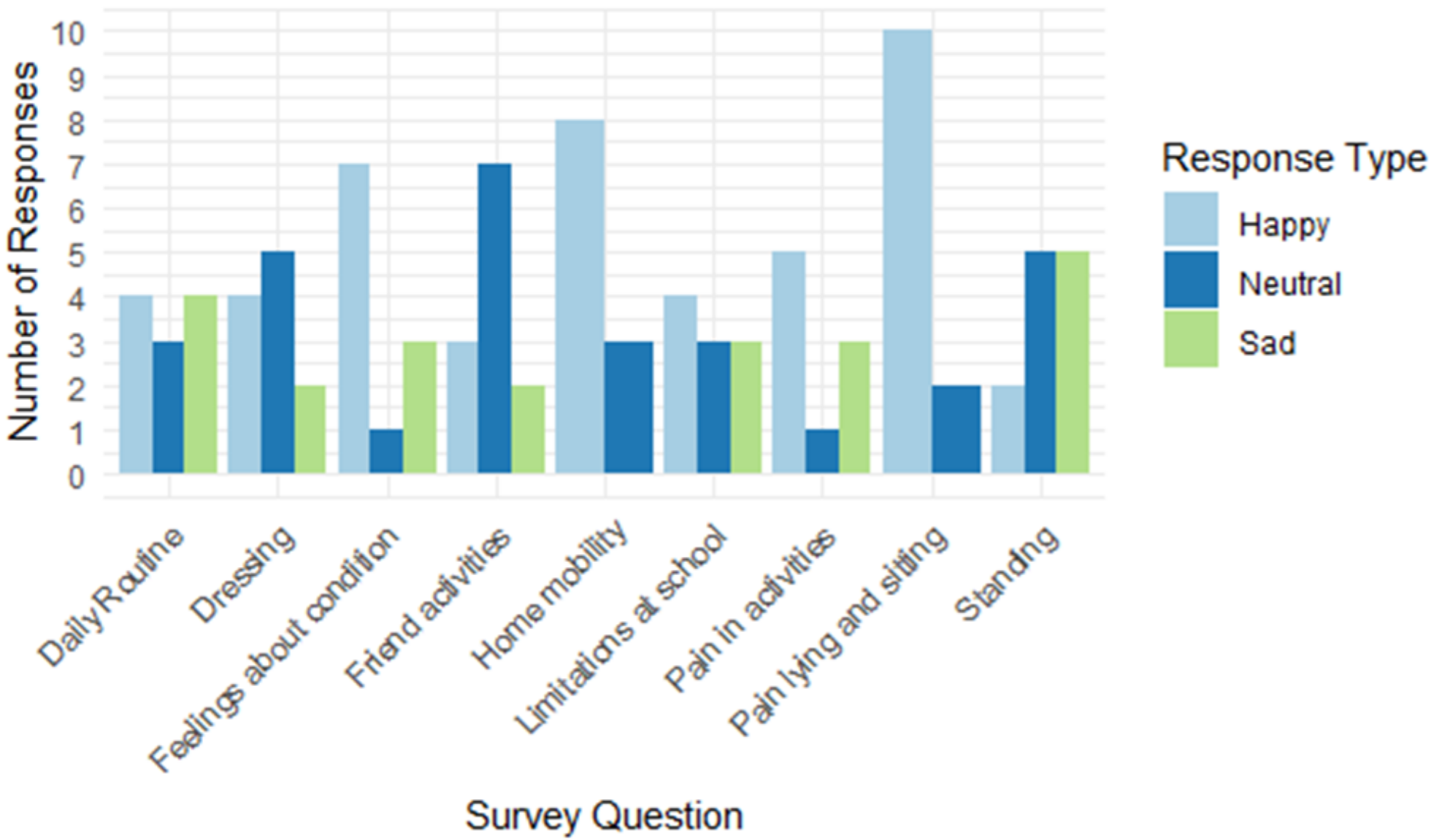


Figure 2

Conclusion

Spinal dysraphism has a multifactorial impact on patient and family quality of life spanning the societal, mental, and physical domains. This knowledge will be integral to the development of patient centred care and will inform ongoing work to create a set of core outcomes for use in the clinical and research settings (1).

References

1. Leo DG, Green G, Eastwood DM, Bridgens A, Gelfer Y. Development of a core outcome set for the orthopaedic management of spinal dysraphism: a study protocol. Bone & Joint Open. 2022 Jan 14;3(1):54–60.