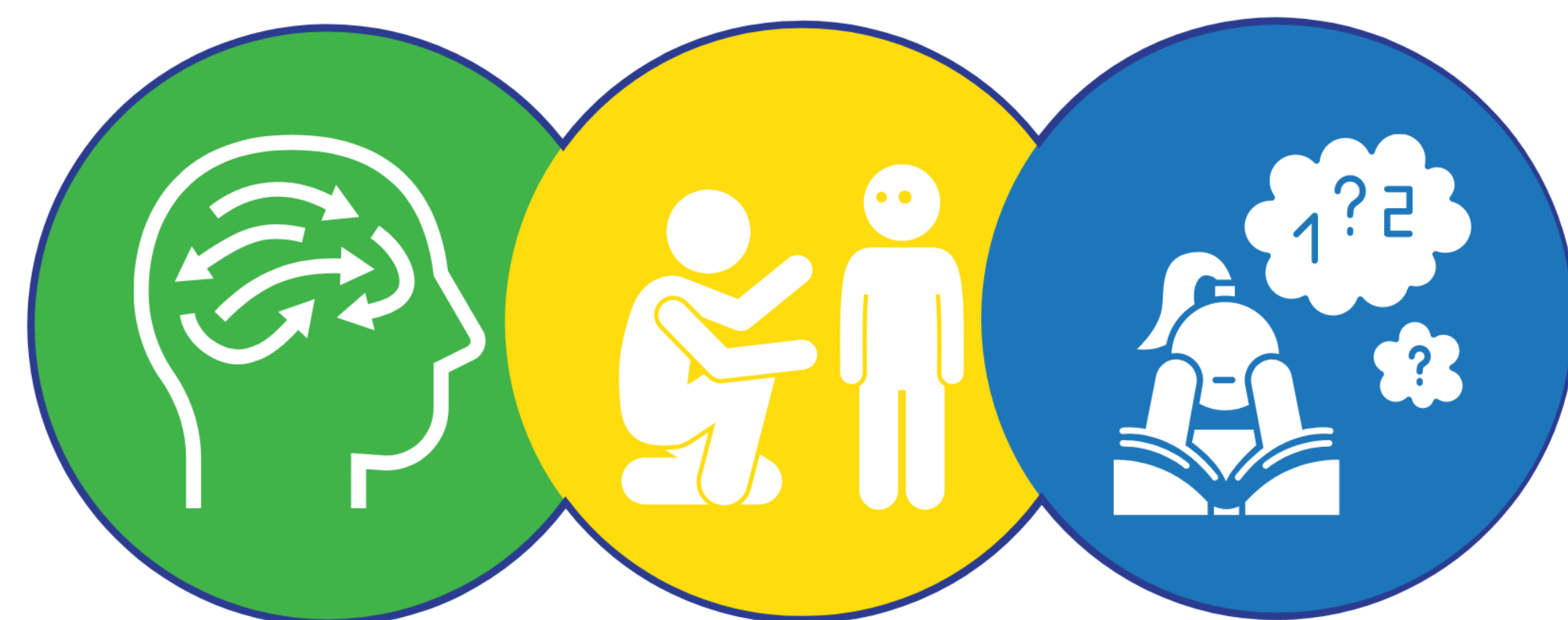


INTRODUCTION

Social Pediatrics (SP) is a discipline that aims to mitigate the effects of the social determinants of health on a child's well-being and development [1]. Negative health outcomes have been seen in individuals impacted by: poverty, food insecurity, inadequate housing, and traumatic events [1]. SP takes a community-level approach in addressing the needs of children and families in an individual, family, and societal context [1,2]. In particular, children who come from socioeconomically disadvantaged households are more likely to develop behavioral problems [3]. Other factors, such as social incompetence; inadequate daily living skills; child health problems; negative life events; and parental mental health problems are strong predictors of behavioural disorders in children [4].

Diagnoses of behavioural conditions, such as attention-deficit/hyperactivity disorder (ADHD) have become alarmingly widespread among today's children and youth [6]. These affect academic achievement, social interaction, and the child's quality of life [7]. This is unsurprising given ADHD is characterized by impulsivity, inattention, and hyperactivity [8]. Further, children who have experienced trauma, toxic stress, and difficult social conditions, like poverty and food insecurity, have been shown to mirror symptoms of ADHD or Autism Spectrum Disorder (ASD) [9,10].



New Brunswick (NB) has been highlighted as a leader in the area of SP and implementing an Integrated Service Delivery framework to help children and youth with complex care needs [1]. In 2017, the Government of NB launched its Family Plan to improve timely access to appropriate services and collaboration across care pathways [11]. A need for children and youth who face behaviour-related issues include timely access to health care professionals for improved well-being at home, school, and within the community [12]. Despite collaborative efforts, the current model of care poses issues of concern. Children often wait 6-12 months for their pediatric appointment, only to be referred elsewhere (e.g., occupational therapists, speech and language pathologists, social workers, psychologists, etc.). This misalignment of family and PCP perception of pediatric care and the services provided can result in a negative pediatrician-family relationship as well as further delays to appropriate treatment for the child [13-15]. Treatment for disorders like ADHD are integral to the child's development because, if left untreated, the overall prognosis for these children is poor (e.g., poor academic achievement and low social functioning) [7]. Research also has demonstrated that this population often requires services from other health allied professionals, suggesting a level of complexity [12].

OBJECTIVES

The purpose of this study is to explore the experiences of caregivers for children with behaviour-related disorders. The study aims to understand the strengths and barriers to accessing and receiving care for these children and their families.

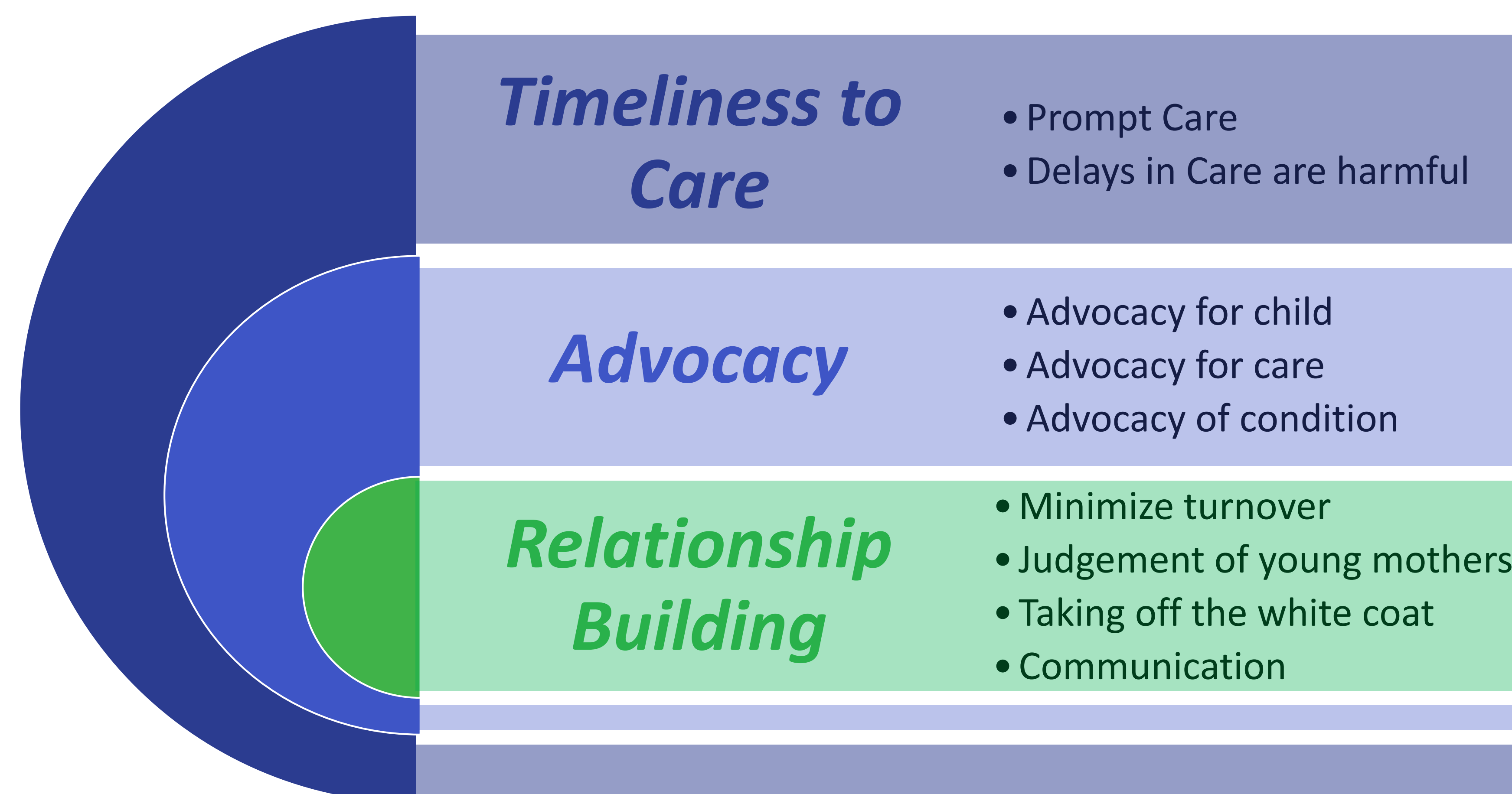
METHODS

Data Collection: 64 caregivers responsible for a child who received care from a pediatrician in a medium-sized NB were contacted. A total of 13 participants agreed to participate in one of three focus groups. Focus groups lasted 45-60 minutes in length. Two focus groups took place via Zoom, a videoconferencing service [16]. Zoom was chosen as an appropriate platform to conduct focus groups because of its ease of use, cost effectiveness, and security and data storage features [16]. One of the focus groups was in-person. Participants were questioned about positive and negative experiences when dealing with the healthcare system in regards to their child's care; details regarding the due course of referral; diagnosis and treatment; and the effectiveness of communication in regards to care between healthcare professionals.

Data Analysis: The data from the focus groups was analyzed using the six steps of inductive thematic analysis devised by Braun and Clarke (2006) [17]. Codes from the focus groups were compared between members of the research team to ensure trustworthiness and internal validity of the results obtained.

RESULTS

Preliminary findings suggest that caregivers value pediatricians who spend time, communicate, and make a human connection with their patients. Barriers included physician turnover, long wait times for referrals, and a lack of knowledge regarding services and programs available in their area. Three major themes emerged from this study including: (1) Timeliness to Care, (2) Advocacy, and (3) Relationship Building.



CONCLUSIONS

Caregivers play an integral role in understanding the needs of their child and communicating those concerns to a care team. This study highlighted the importance of the timeliness to care for children with behaviour-related disorders. Early intervention has an important role in the prognosis of a child's development and social functioning at home and in school. Caregivers felt that delays in care can be harmful to the overall well-being of the child.

The theme of advocacy was pertinent in this study. Caregivers felt that they had a great responsibility to advocate on behalf of their children to receive care and have their condition acknowledged by the care team. Some participants felt that certain members of the care team were not equipped to handle the complexity and coordination of care required for a child with a behaviour-related disorder.

Caregivers felt that the value of good care was dependant on the relationship developed between themselves and members of the care team. Caregivers who had positive rapport and consistent communication with the team felt that their child was getting necessary care. Caregivers appreciated when physicians were able to "take off the white coat" and relate to their child at their level. Allowing children to be more vocal and involved in their care made caregivers feel that a true therapeutic relationship was being made. Less judgement resulted in caregivers opening up to providers about social circumstances influencing their child's condition. Consistent care with minimal turnover contributed to better integrated care for the child.

Children with behaviour-related disorders are a complex patient population who require streamlined and integrated care. This study is important as it contributes to our knowledge on the role SP can play in the care of children with complex care needs. It was recommended that an advocate or navigator could improve access and care coordination.

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