

# Scoping Review of Medical Home Model Use During Emerging Adulthood for Autistic Individuals

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## Introduction

The medical home model aims to provide collaborative comprehensive and preventative care with the patient themselves as the core of the care team (Cooley et al., 2003; Palfrey et al., 2004), leading to benefits such as increased general care quality and patient satisfaction (Rosenthal, 2008). Autistic individuals have a lower utilization of primary care which is especially reduced after the transition to adulthood (Hand et al., 2021). Therefore it is important to understand the current landscape of the studies on the medical home model for autistic populations.

## Objectives

Our scoping review intended to assess the current state of literature regarding the use of the medical home model with autistic individuals in the time of transition considered emerging adulthood, generally ages 18 to 25. We wanted to determine how much work was being done in this area, what population samples were included in this research, and what themes the research was focusing on. We were particularly interested in definitions and measurements of quality of care and patient self-determination, as well as attention to transitional support between pediatric and adult services.

## Methods

We followed the framework laid out by Arksey and O'Malley's Scoping studies: towards a methodological framework (Arksey & O'Malley, 2005) including the first 5 steps of (1) identifying research questions, (2). Identifying relevant literature, (3). Studying relevant literature, (4). Charting data from literature, (5). Reporting review results. A modified version of the Cochrane review checklist was used to guide coding and extraction of relevant articles. The following search terms: allintitle: autism "medical home"; autistic "medical home"; auti\* AND "medical home model"; and (auti\*) AND ("medical home") were used. Searches were performed of Google Scholar, PubMed, and the UC library search. Papers were excluded based on date range, lack of medical home focus, relevance, review status, and more. Specific inclusion criteria were the presence of an autistic patient group and including ages of transition and adult care.

## Results

The patient population demographics are as follows: Nine out of ten papers had patient populations that were based in the United States and one paper was based in the European Union. Six out of ten papers had a majority male patient population, one out of ten papers had a majority female patient population and three out of ten papers did not specify biological sex or gender identity. The age range of all papers was 0 to 68 years old with the average age of the patient populations ranging from 10.9 to 29 years old. The following graphs show the results of our thematic analysis:

Figure 2: Prevalence of Patient Directed Care

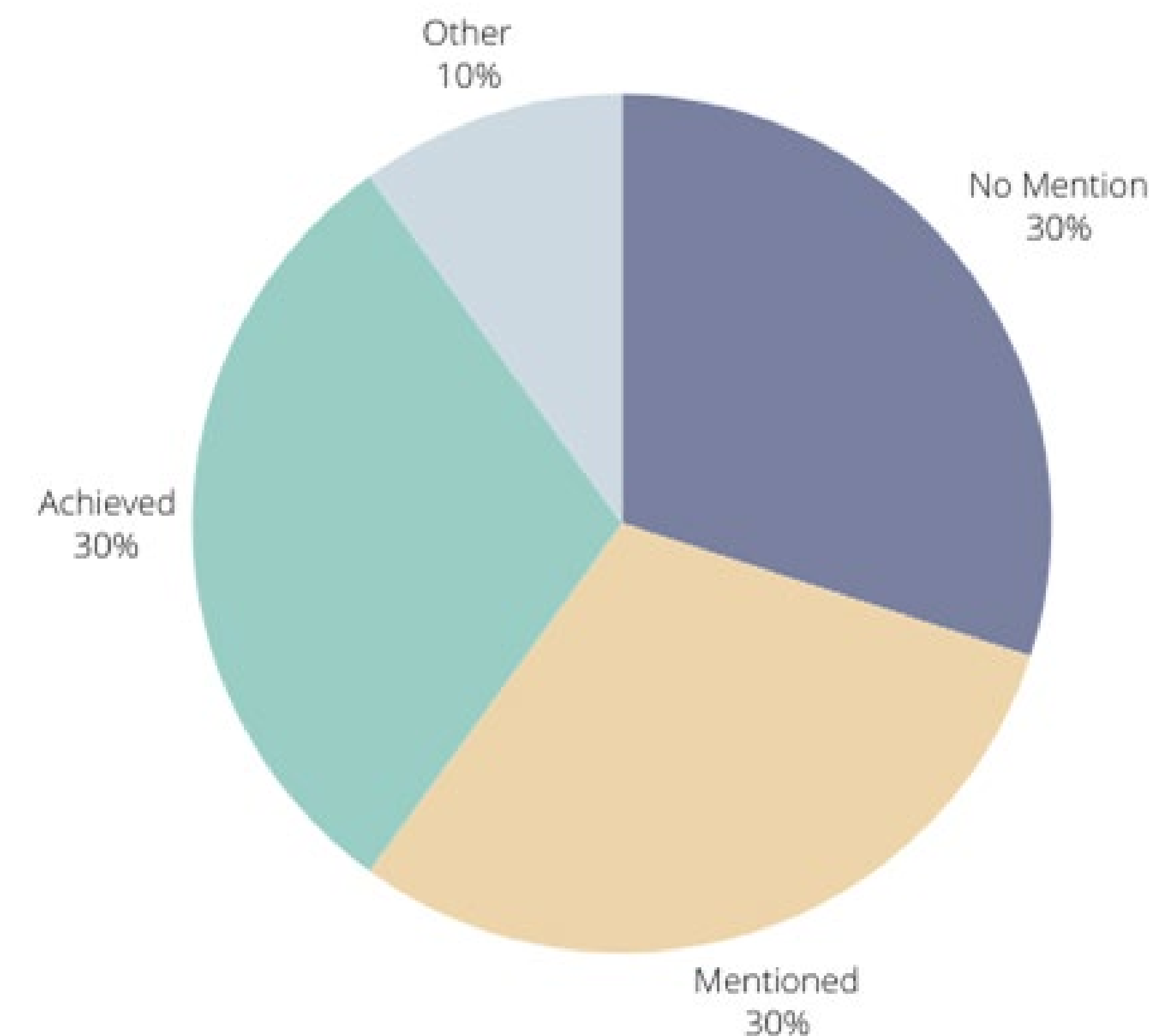


Figure 3: Evaluation's Majority Perspective Source

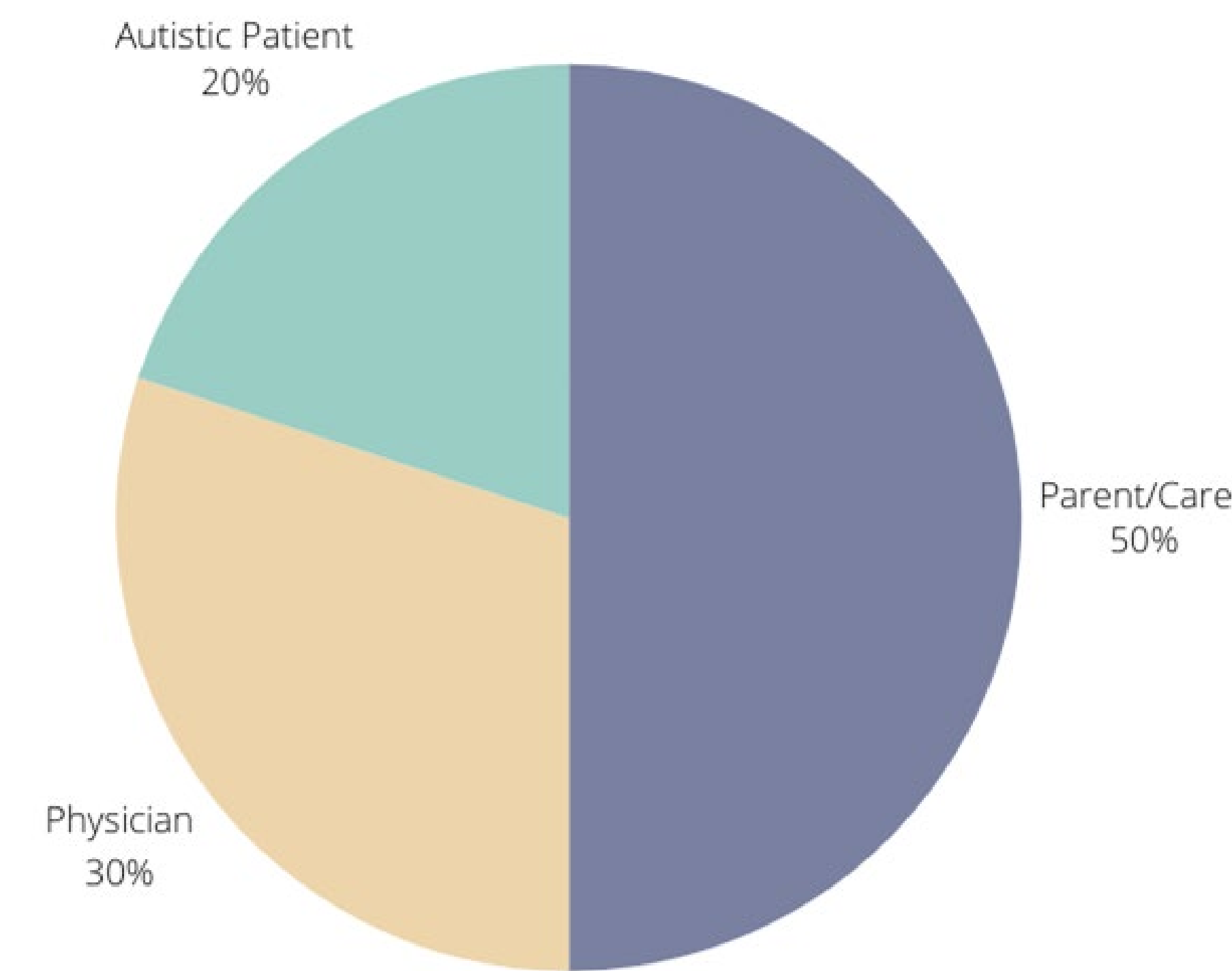


Figure 4: Prevalence of Themes & Focus of Paper

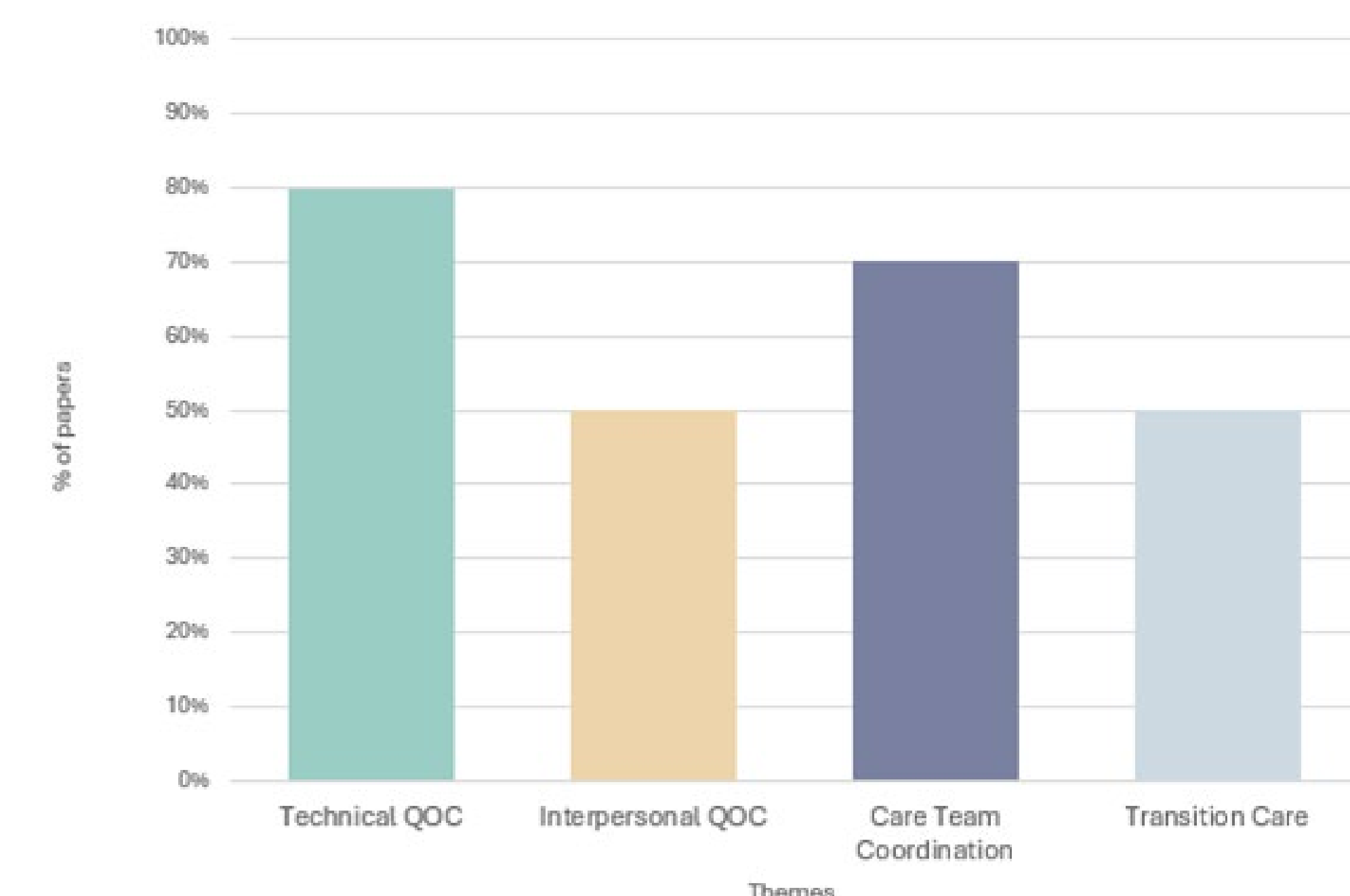
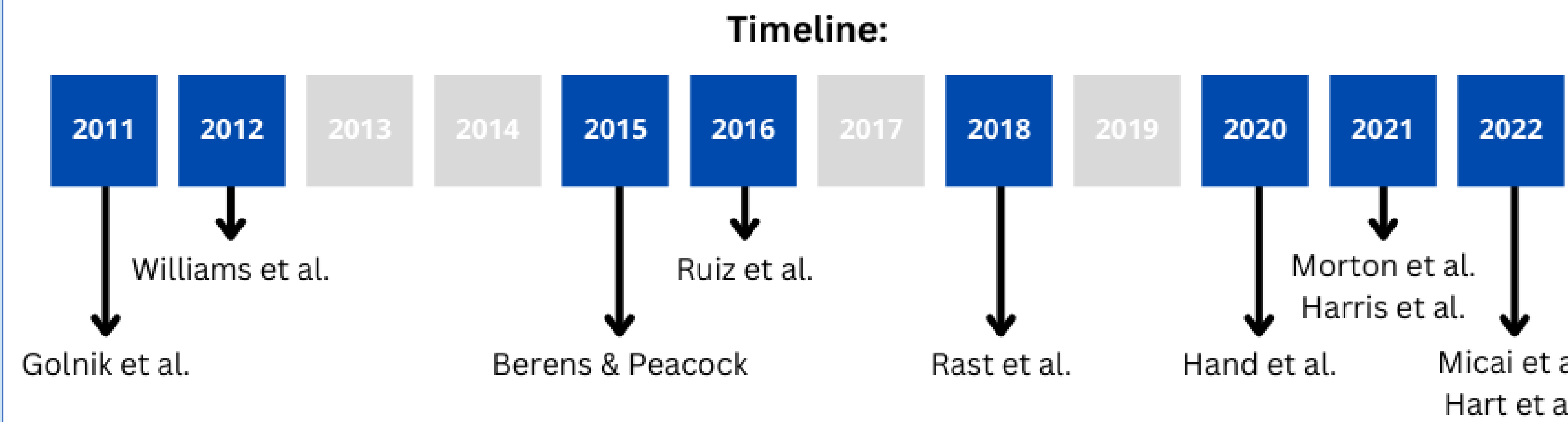


Figure 1: Published Year Timeline of Studies



## Conclusions

We found that while all studies reviewed covered some type of patient care, the most common was technical quality of care followed by care team coordination. Interpersonal quality of care and transition care were the least common forms of care studied. Even so 50% of papers covered these themes. While it is clear that care is an area of concern in these studies, the care is not always explicitly patient-centered. The thematic analysis shows a dearth of research in this field centering on the voices and experiences of the autistic stakeholders. While less than 1/3 of the papers reviewed examined patient-directed care and self-determination, it was also not uncommon for studies to acknowledge the importance of self-advocacy and patient-centered care without actually using any relevant outcomes. The majority of the studies did not focus on the voices and perspective of the autistic patients, instead, they relied on the opinions and voices of the physicians and carers. It is clear that a gap exists in the current literature when it comes to a patient self-determination. Future research should center on the voices and autonomy of patients.

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\*Denotes publications included in scoping review



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