

# Transferring self-management responsibilities in type 1 diabetes families: Initial assessment of individual and family self-management theory

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**This study aimed to chart the nature of responsibility transfers between parents and children with type 1 diabetes (T1D), as well as assess the suitability of individual and family self-management theory, proposed to describe general coping with chronic conditions, in framing such transfers. Eight in-depth telephone interviews were conducted with four mothers and their adult children with T1D. Through inductive thematic analysis, parental communication, social network engagement and technology advancements were revealed as key factors in facilitating successful transfer. Two types of responsibility transfer were identified: long-term and linear (parent passes self-management responsibilities to the child as they grow older), and short-term and temporary (child seeks to momentarily pass responsibility for daily tasks back to their parent, to take a break from T1D). Greater focus on facilitators of transfer can ease transitions from paediatric to adult diabetes care.**

Type 1 diabetes (T1D) accounts for more than 85% of all diabetes cases in individuals under 20 years old (Maahs et al, 2010). These youths often rely on their parents to execute daily responsibilities to maintain acceptable blood glucose (BG) levels until they are able to learn these skills for themselves (Iturralde et al, 2017). Diabetes distress is linked to poorer glycaemic control and treatment adherence, and is associated with children's negative views on self-management (Strandberg et al, 2014; Hagger et al, 2016; Jaser et al, 2017). As the transition from childhood to adulthood is a key turning point where conflicts between children and parents can affect future condition management (Peters et al, 2011; Zysberg and Lang, 2015), positive communication patterns are important in ensuring the continued practice of self-management strategies and treatment adherence as the child ages (Iskander et al, 2015; Jaser et al, 2017; Martin et al, 2001). There are three types of

management tasks in chronic illness care (Corbin and Straus, 1985):

- Medical (BG tests and injections)
- Behavioural (adherence to daily tasks)
- Emotional (receiving support from social networks as well as managing their own thoughts and feelings about T1D).

One proposed approach for capturing the diversity of responsibilities that patients face is individual and family self-management (IFSM) theory (Ryan and Sawin, 2009), which analyses the impact of different individual, family, physical and environmental factors on patients' lives, see *Figure 1*. To date, three papers have applied IFSM theory to T1D: two cross-sectional quantitative studies (Polfuss et al, 2015; Verchota and Sawin, 2016) and a descriptive account of what is known about self-management and chronic illness in general, which mentions T1D as an example (Grady and Gough, 2014). Verchota and Sawin (2016) measured the extent of self-management behaviours

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## Article points

1. Both long- and short-term transfers of responsibility from parent to child with type 1 diabetes occur as the child matures.
2. Good maternal-child communication and strong social networks are key influential factors in responsibility transfer.
3. Individual and family self-management theory's conceptual framework captures responsibility transfer but should be updated to reflect the impact of emerging technologies on diabetes self-management.

## Key words

- Communication
- Family
- Responsibility
- Self-management
- Type 1 diabetes

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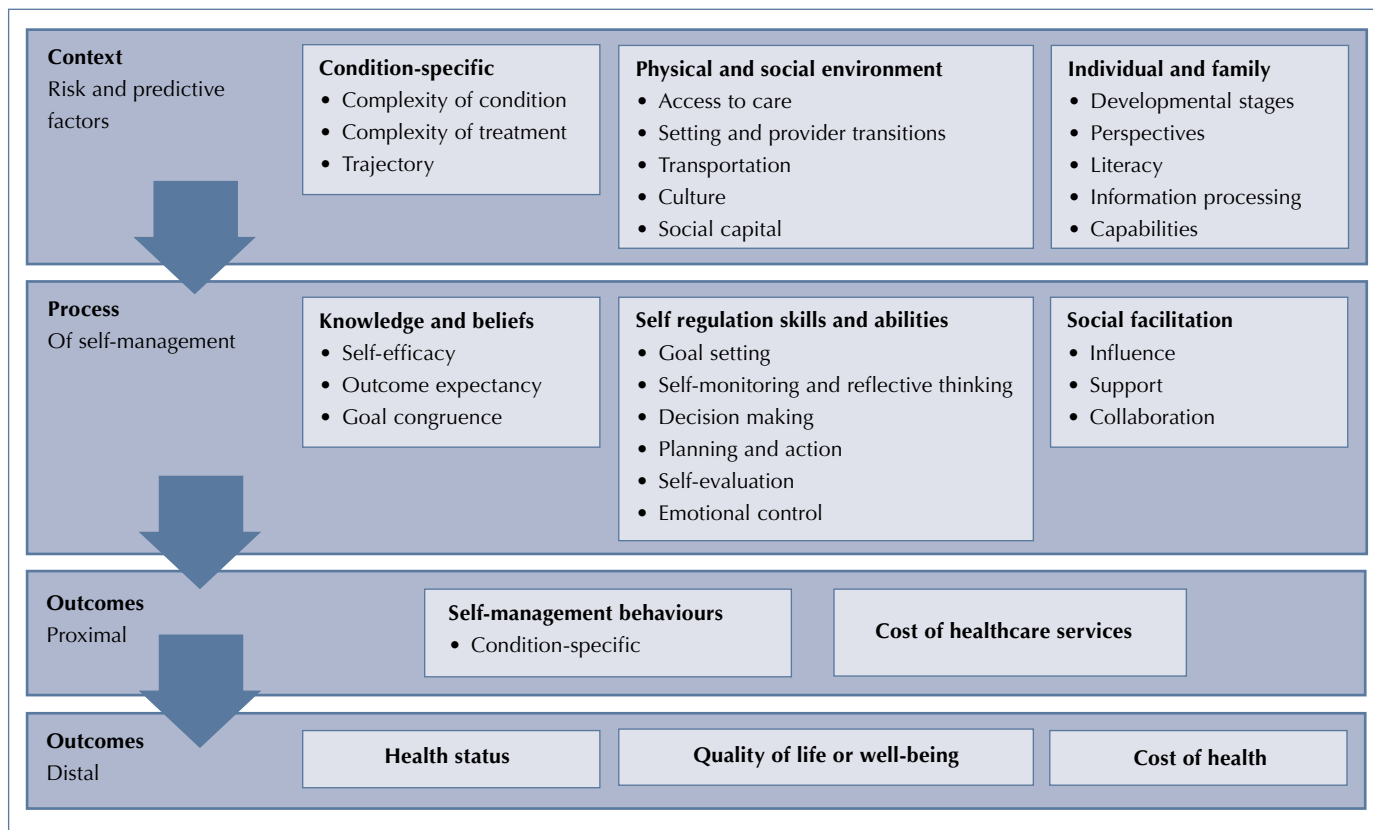


Figure 1. Individual and family self-management theory: proposed factors and their components (Ryan and Sawin, 2009)

explained by context and process variables as categorised by IFSM theory, assessed via indicators attached to proximal and distal outcomes. Using hierarchical multiple regression and collecting data on variables through surveys, they found that depressive symptoms and communication variables (representing context and process dimensions) together explained 37% of variance in BG control. Their study affirmed the IFSM framework as a viable model for understanding key aspects of T1D self-management. Polfuss et al (2015) collected data on families’ evaluations of a diabetes transition programme through questionnaires related to knowledge, self-efficacy and self-management practices. They surveyed parent–child pairs independently and found greater emphasis is needed on sustaining long-term health-promoting behaviours. They state that IFSM theory is promising in ‘developing interventions to improve self-management behaviours and subsequent health outcomes’ (Polfuss et al, 2015). A drawback is that teenagers were asked about their current experience, thus retrospective evaluations of their experiences

over time are lacking. Grady and Gough (2014) highlighted the contribution of nursing science to the implementation of theoretical self-management frameworks in interventions for arthritis and T1D.

Significant gaps remain in the literature on how care responsibilities are shared and transferred over time within families who have a child with T1D. The primary aim of this study was to investigate how transfer of self-management responsibilities occurs between parents and children with T1D through analysis of individual, family and environmental factors. Its secondary aim was to assess the usefulness of IFSM theory in framing this responsibility transfer, given that this theory has been developed broadly for all chronic illnesses.

### Method

Four UK families consisting of one parent, who was the main caregiver, and one child diagnosed with T1D before age 10 and currently aged at least 20 years, were recruited via Facebook T1D groups. There were no ethnicity, income group or other restrictions.

A phenomenological approach with thematic analysis was chosen to gain a qualitative understanding of participants' lived experiences of responsibility transfer. In-depth, open-ended interview questions were guided based on themes (eg school environment, social networks, parental communication) identified through the literature review and the author's own experience with T1D. Themes were set prior to the interviews, although they were amenable to change according to participants' accounts. Parents and children were interviewed separately to mitigate the risk of interviewees' answers impacting each other.

Audio-recorded telephone interviews were conducted between June and August 2018. During playback, identified themes were organised into rows in Excel using systematic data synthesis. There was no post-interview alteration of themes. Although full transcription was not undertaken due to limited time and resources, timestamps and key quotations were noted for important passages in each audiotape, so data were easily retrievable during subsequent analysis.

Files were stored on an encrypted campus desktop, accessible only to the interviewer and supervisor. The study was approved by the LSE Research Ethics Committee.

## Findings

Using IFSM theory as a guide, data were broadly separated into factors mediated by physical and social environment or individuals and their families. The key influential factors are given in *Figure 2*.

### Physical and social environment

#### School

Three families felt that schools were unhelpful in adjusting to their child's needs and referenced social exclusion due to lack of awareness by other parents and staff. Family 4 (F4) reported a positive experience, but this was most likely due to staff members taking the initiative to educate other students after the mother informed them of her child's needs. Three children did not have issues with BG control until university; F4 child attributes poor control during her teenage years to a negative attitude to self-management responsibilities. F1 and F4 children reported difficulties in coping with the

additional freedom that came with living away from parents, but F1 learned to adjust and F4 attributed her better management to attendance at the Dose Adjustment For Normal Eating (DAFNE) course after completing her degree.

#### Social networks

F1–3 families attended diabetes conferences and were members of online support groups, which played a significant role in the emotional management of T1D. They were introduced to new friendship networks and activities such as BG testing and carbohydrate counting were normalised. All children agreed that such events made them more receptive to learning about self-management and working with their families on their care. Mothers concurred they understood how much emotional support children received by being around others like them: 'only another type 1 [child] will understand how she feels' (F3 mother).

#### Technology

F1–3 children switched from injections to insulin pump therapy when aged between 10 and 15. F4 child began in her mid-twenties.

#### Medical staff/specialists

Most medical help was limited to insulin pumps or regular check-ups. Mothers did not receive emotional support from staff and the children recognised how their mothers shouldered most responsibilities. F4 child credits the DAFNE programme for her improved self-care now because she believes it 'motivated me to take better care of myself'.

### Individual and family factors

#### Communications on daily self-management and long-term consequences

F1–3 mothers reported including children as much as they could in daily decision-making. F1 child recalls: 'Mum made sure I was always involved in every decision... she would talk with me to the doctor [rather than excluding me].' Generally, communication was very open between all mothers and children, which contributed to all interviewees feeling that responsibilities were transferred 'naturally' as the child grew up. All mothers attested to addressing long-term consequences and

### Page points

1. Parents and children were interviewed separately and identified themes were organised using systematic data analysis.
2. Data were separated into factors mediated by physical and social environment or individuals and their families.
3. Families felt schools were unhelpful in adjusting to their child's needs.
4. Children felt diabetes support groups made them more receptive to learning about self-management and working with their families on their care.

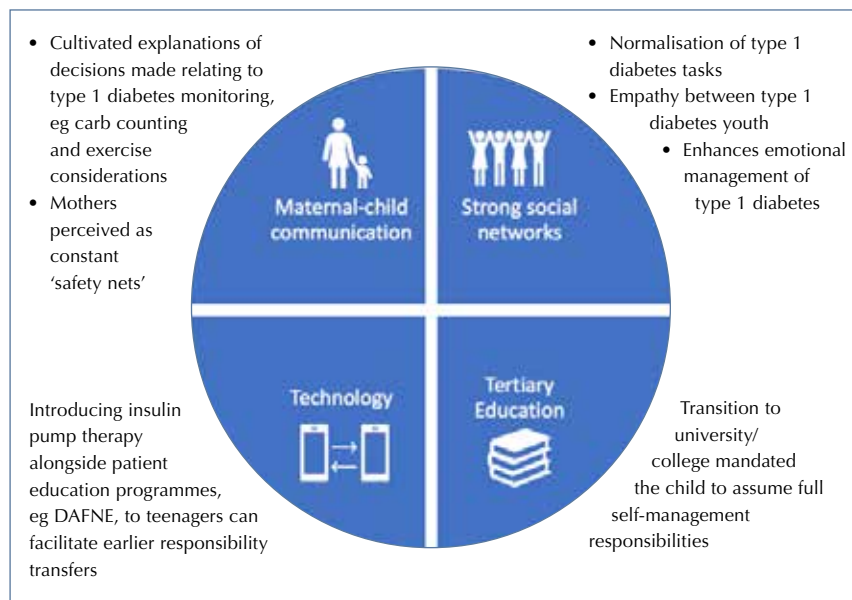


Figure 2. Summary of key influential factors facilitating successful responsibility transfers

F1–3 children reacted positively, stating this sort of communication helped instil the importance of good self-management. F4 child felt frequent reminders about future risks 'desensitised' her from seeing their severity, although overall there were no major family conflicts in this area. In general, siblings did not greatly impact responsibility transfers or self-management.

#### Parental monitoring and developmental stages

Parents assumed the primary responsibility for teaching children how to carry out daily T1D-related activities. F4 mother taught her child how to do these at 'around 5 years old' and her child appreciated the increased freedom she had as a result: 'I didn't feel restricted in my social life 'cos I didn't need to rely on my parents.' F2 mother noted how the way she talked about T1D changed over time, with her child confirming she preferred to initiate discussions as she grew older. Overall, as children understood more about T1D management, they gradually learned more about how to carry out daily routines, which led to improved BG levels.

All children viewed their mothers as constant 'safety nets' whom they could consult regarding any uncertainties with T1D (eg figuring out what caused hypoglycaemic episodes). Similarly, all mothers knew their role as their child's main source of medical and emotional support when

they encouraged children to be more independent in their daily care. Three mothers echoed the sentiment that they were still the 'back up' when their child moved away for university. All mothers were aware of the lifestyle changes their children would experience during this developmental stage, including being exposed to alcohol and dating. A prime concern for the children was being physically far from accessing maternal emotional and medical support when not living at home. The case was slightly different for F4: the child moved away before attending university, so her independence with self-management occurred earlier than the others. This independence did not necessarily entail good BG control, as F4 mother and child mentioned the negative impact of non-diabetes-related family issues.

#### University and adulthood

F1–3 mothers voiced concerns over aspects such as greater independence or not being able to monitor the risk of nocturnal hypoglycaemic episodes when their children moved away to university. F1–3 children reported that this was a significant transition period for them, since it was when they adopted most responsibility over their own care. F3 child noted: 'Moving out of the family home gave me that big push... I may not have taken on as much of the responsibilities if I hadn't moved out.' Nevertheless, parents reassured children of their continued emotional support.

Most mothers explained how they remain somewhat involved in executing routine T1D tasks, even now their children are adults. F3 mother noted that she assists with her child's insulin pump site changes 'because of her back problems'. These momentary transfers of self-management responsibility are also characterised in F2 child's account: she admits to asking her mum to do her midnight BG tests and 'bring me Jelly Babies' during hypoglycaemic episodes. However, F1 child notes such transfers are not structured: '[Parents] would never ask me to take on responsibilities but if I'd tell them I can test myself at midnight, they would say fine but we are here as back-up.'

#### Discussion

This study investigated the transfer of self-management responsibilities from parents to

children with T1D via retrospective in-depth interviews, with the secondary aim of assessing the usefulness of IFSM theory in framing this responsibility transfer. Thematic analysis revealed that two types of transfers occur simultaneously: one linear, long-term transfer of technical and behavioural management from parents to children, and another momentary, short-term transfer of daily tasks that go back and forth between the two parties, according to the child's wants, see *Figure 2*. The latter is guided by the child, caused mainly by their desire for temporary relief from the 24/7 demands of the chronic condition, and can occur during adulthood. The former is completed by the time they finish university. All participants agreed that self-management responsibilities were transferred gradually but unevenly: moving away from home sparked a larger transfer compared to others (eg transition from childhood to adolescence). Such a stage conferred both greater independence and greater responsibility in managing BG, because children could no longer physically rely on their parents.

Key influential factors were good maternal–child communication and strong social networks. This study found that the mothers' explanations of their decision-making processes had a protective impact against future avoidant coping behaviours in the children interviewed. Most reported no major self-management difficulties during adolescence or any significant conflicts; issues stemmed from unwelcoming school environments or university transitions. There was no link between increased autonomy at university and avoidant behaviour when faced with problems. A potential reason for the absence of diabetes distress could therefore be attributed to positive communication established early on. This explanation supports Hagger and colleagues' (2016) finding that gradual education and immersion into T1D responsibilities helps emotionally strengthen children for independent living.

Parental guidance greatly influenced all three process components of IFSM, see *Figure 1*. For instance, one parent explained how she used consultant appointments, which tackle the technical management of BG levels, to boost her child's confidence in leading those types of discussions, empowering her child to take on more

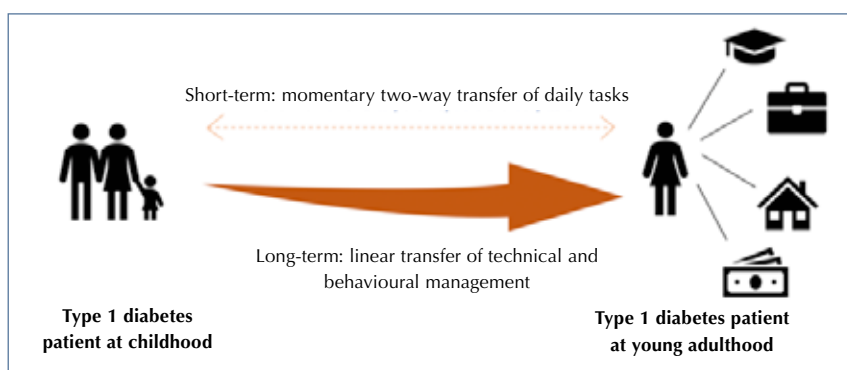


Figure 3. Transfers of self-management responsibilities between parents and a child with type 1 diabetes over time

responsibility. This supports findings from the literature that trusting parent–child relationships are important in minimising conflict during adolescence (Babler and Strickland, 2015).

While there was no mention of non-attendance at diabetes-related events as a cause of worse self-management, data suggest that participating in online and offline support groups and conferences normalised T1D tasks and facilitated more effective responsibility transfers while protecting children against emotional burnout.

An interesting finding is that an individual's social and physical environment, thoughts or cognitive processes and actual behaviours have a reciprocal impact on one another, ie 'reciprocal determinism', as mentioned in Ryan and Sawin (2009). This is most notably manifested in improved diabetes management once the children understood more about the condition, its consequences and how to leverage technology use and social support. While this concept took effect earlier on for F1–3 children, F4 child reported eventually improving her care via DAFNE and acquiring her insulin pump. It seems that patients' understanding of factors affecting glycaemic control and self-management habits, whether instilled by parents or training programmes, encourages further adherence.

Lastly, technology and accompanying patient education programmes were particularly influential. Given that IFSM theory did not fully account for these influences, greater attention should be given to these factors when applying this theory to other chronic conditions.

The results of this research should be interpreted with caution. Facebook recruitment limited the

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participant pool to active members of T1D groups. Participants were female, British, had good access to social media and attended university, and were therefore not representative of the wider population, limiting the generalisability of the findings. These families may have been more willing to share self-management successes in the first place. Data analysis was conducted by the author alone with guidance from the MSc supervisor, which limited the depth of thematic analysis.

### Application in practice

Practitioners should take note of how integral parents' roles are in ensuring children adopt good T1D self-management practices, especially when transitioning from paediatric to adult care. The intermingling of IFSM context and process factors should be better appreciated in discussions about how to improve adherence to daily routines during transition to adult care, especially the value of social networks gained from family-oriented conferences.

Technology can facilitate earlier responsibility transfers alongside patient education programmes (eg DAFNE) and should be considered a potential route to assisting with transitions to independent living. A recent integrative review by Chaves et al (2017) reported that functionalities such as alarms, data recording and even supporting certain behavioural changes are 'essential' in adolescents' BG control. Adolescents are increasingly using mobile applications (Kumah-Crystal et al, 2015); promoting usage of apps like Carbs & Cals and On Track could complement adolescents' use of mobile apps to keep in contact with their parents, giving them easy access to a remote form of emotional and technical support. Not only can younger patients' technology usage facilitate – indeed encourage – them to take on more self-management responsibilities, and hence ease responsibility transfer, but it also allows better glycaemic control which, in light of reciprocal determinism, may further encourage long-term adherence.

For researchers, this study's qualitative findings add to a small but growing body of research on how social units adjust to live with chronic illnesses. Interviewing both parent and child in this retrospective nature allows their hindsight to supplement descriptive accounts of their experiences, sharpening the conceptualisation of

how responsibility transfer precisely occurs. Due to the complexity of the relations between categories and their sub-components in IFSM theory, this study provides a method to investigate select factors and their impact on each other. While the cross-sectional nature of the previous two studies on T1D and IFSM mean that relationships identified are not necessarily causal (Polfuss et al, 2015; Verchota and Sawin, 2016), an increasing number of researchers are beginning to accept that qualitative studies can help shed light on causal relationships (Maxwell, 2014). My study found that interviewees' experiences affirmed likely causal relationships between some factors in the context and process dimensions, for instance, parental encouragement can boost the child's confidence in doing their own BG tests, which enhances their self-efficacy.

### Conclusion

Although the participants are not a representative sample of the wider young adult T1D population, the findings of this study provide insight into the nature of T1D responsibility transfers until young adulthood. Further research is needed before the findings could be used to guide programmes for older adolescents. IFSM's conceptual framework is appropriate in capturing responsibility transfer but should be updated to reflect the potential for emerging technologies in assisting self-management techniques. ■

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